

Not included, not engaged, not involved:

A report on the experiences of autistic children missing school



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CHAPTER 1 - INTRODUCTION

“Excellence and equity for all” is the Scottish Government’s vision for education in Scotland. This aspiration fits with Scotland’s inclusive and forward-thinking approach to education policy, and there is an extensive programme of work happening to make this a reality. The Scottish Government reports progress is being made¹, including improvements in the number of children with additional support needs leaving school for positive destinations and increased funding of additional support for learning from £527m to £584m between 2013 and 2015-16². However, for a significant minority of children, excellence and equity is a long way from their lived experience.

There are growing concerns in Scotland about the educational experiences of pupils with additional support needs, and in particular of autistic children. A number of reports³ have highlighted some of the pressures in education in meeting the support needs of autistic pupils. There is also significant anecdotal evidence from organisations supporting autistic children and their families that some autistic children are not having their right to an education fulfilled, and are missing a significant and concerning amount of school.

As well as through formal exclusions from school, instances have been reported of autistic children being excluded from their education in other ways. This includes the use of part-time timetables, children missing school due to anxiety or other health needs, and a lack of suitable school placement or support meaning a child is unable to be in school. There are also concerns that many families are being asked to pick their child up from school early on a regular basis, without the child having been formally excluded – a practice which is unlawful. This picture is at odds with the intentions outlined in Scottish Government policy guidance on the management of attendance, absence and exclusions in schools, ‘Included, Engaged and Involved’ parts 1⁴ and 2⁵.

Growing concerns about these issues across all the partners led to us coming together to try and gain a deeper understanding of the experiences of these pupils and their families. We sought to understand the amount of time some autistic pupils are missing from school and the reasons why this has happened, whether alternative arrangements for their education have been put in place, what support has been offered to return to school, and importantly, what the impact on the children and young people and their families has been.

1 Delivering Excellence and Equity in Scottish Education: A Delivery Plan for Scotland (Scottish Government, 2016): <https://beta.gov.scot/publications/delivering-excellence-equity-scottish-education-delivery-plan-scotland/>

2 Response from Scottish Government to ASL Report. July 2017 http://www.parliament.scot/S5_Education/General%20Documents/20170726InResponseFromScottishGovernmentToASLReport1.pdf

3 See Chapter 3

4 Included, Engaged and Involved Part 1: Attendance in Scottish Schools (Scottish Government, 2007): <https://www.gov.scot/Publications/2007/12/05100056/0>

5 Included, Engaged and Involved Part 2: A Positive Approach to Preventing and Managing School Exclusions (Scottish Government, 2017): <https://www.gov.scot/Publications/2017/06/8877>

As a starting point, we decided to focus on hearing from parents of autistic children about their child's experiences of missing school within the last two years. Each partner organisation has links and contacts with a broad range of individual parents and support groups, and as such we were able to reach a substantial number of parents from across Scotland. Our survey was advertised online for a period of three weeks in early 2018, receiving 1,434 responses covering every local authority area.

We strongly believe that the experiences of autistic children who are missing out on their education should be seen as a priority for action for those in positions to make positive changes and ensure these children's rights are fulfilled.

Using evidence from the survey, and considering the wider ambitions of the Scottish Government for all children, we have made nine calls to action and several recommendations for further work.

Over the coming months we will be working together and with the relevant stakeholders and decision makers to make these calls a reality.

About the partner organisations

Children in Scotland

Giving all children in Scotland an equal chance to flourish is at the heart of everything the organisation does. By bringing together a network of people working with and for children, alongside children and young people themselves, it offers a broad, balanced and independent voice. It creates solutions, provides support and develops positive change across all areas affecting children in Scotland. The charity does this by listening, gathering evidence, and applying and sharing its learning, while always working to uphold children's rights. Children in Scotland's range of knowledge and expertise means it can provide trusted support on issues as diverse as the people it works with and the varied lives of children and families in Scotland.

Children in Scotland manages Enquire, the Scottish advice service for additional support for learning. Enquire helps children and young people, families and professionals understand children's rights to additional support for learning. Enquire receives 1,500 enquires per year from families and professionals seeking advice and information about additional support for learning.

www.childreninscotland.org.uk

Scottish Autism is an organisation dedicated to enriching the lives of autistic people. They are the largest provider of autism-specific services in Scotland, providing a wide range of innovative support for children and adults, including a residential school for autistic pupils in Alloa. Across all of their services there is a focus on improving quality of life. They create personalised support plans, which are based on an individual's own strengths and motivations and on achieving outcomes which are meaningful to them. Scottish Autism also seeks to share its knowledge and expertise with parents, carers and other professionals in order to support the development of skills and strategies needed to provide the best care and support for autistic people.

www.scottishautism.org

The National Autistic Society Scotland is a leading charity for autistic people in Scotland and their families. It provides local specialist help, information and care across Scotland to autistic people, their families and carers. They offer a wide range of personalised quality support at home and in the community, both in groups and one-to-one. Their branches offer autistic people and families help and mutual support, and their employment team support autistic people in work and their employers. They also have an autism-specific school, Daldorch House School.

Their Education Rights Service provides impartial, confidential information, advice and support on education rights and entitlements. This service launched in 2006 and has supported around 3,500 individual families with autistic children from all over Scotland, many on an ongoing basis. They are one of the few organisations that support families with appeals to the education appeal committee, which decides the outcome of appeals made by parents or young people, including those on matters relating to exclusion from school.

www.autism.org.uk

Note on terminology

We recognise that many individuals and groups have different preferences for describing autism. Throughout this report, we will use identity-first language of 'autistic children/pupils' as standard, as this has been shown to be preferred terminology for many autistic people⁶.

⁶ Kenny, L. et al (2015). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4)

CHAPTER 2 - WHAT SHOULD EDUCATION LOOK LIKE FOR AUTISTIC CHILDREN IN SCOTLAND?

The Young Ambassadors for Inclusion are a group of young people with additional support needs who have been brought together by Education Scotland to share their views and experiences of Scottish education. They have identified five themes that are important for inclusion: friendship, belonging, awareness of additional support needs, positive attitudes, and asking for help and support. One of the Ambassadors has summed this up by saying “We want to be seen as individuals with our own set of unique strengths and skills”.

The Scottish Government annually publishes statistics on the make-up of the pupil population of local authority schools, including the number of pupils who are recorded as having additional support needs due to an autism spectrum condition. Figures for the number of autistic children educated in independent or grant-aided schools, or who are home educated, are not available. According to the most recent figures⁷, there are 14,973 autistic pupils in schools run by local authorities.

This means that autistic pupils make up just over 2% of the total local authority school population in Scotland, and 8% of all children recorded as having additional support needs. 18% of autistic pupils are female, and 82% are male. 44% are in mainstream primary schools, 40% are in mainstream secondary schools, and 16% are educated in special schools. Of those in mainstream schools, some of these pupils may be in specialist bases or units attached to the mainstream school.

The following chapter outlines the main legislation and policy relating to these autistic childrens' right to education, inclusion and support at school. Within this context Scottish education should offer an inclusive, warm and welcoming experience.

Right to education

The United Nations Convention on the Rights of the Child (UNCRC)⁸ sets out the right to an education for all children in Article 28. Article 29 states that this education shall be directed to: “*The development of the child’s personality, talents and mental and physical abilities to their fullest potential*”. These rights have been embedded into Scottish law in the Standards in Scotland’s Schools etc. Act 2000⁹. Article 23 says that children who are disabled should be taught at school in a way that understands their disability, and that works towards them achieving the fullest possible social integration and individual development.

⁷ Pupil Census 2017: Supplementary statistics from the 2017 Pupil Census: <https://www.gov.scot/Topics/Statistics/Browse/School-Education/dspupcensus/dspupcensus17>

⁸ Information about the UNCRC can be found on the Children and Young People’s Commissioner Scotland’s website: <https://www.cypcs.org.uk/rights/uncrc>

⁹ Standards in Scotland’s Schools etc. Act 2000 section 1 and 2(1): <https://www.legislation.gov.uk/asp/2000/6/crossheading/provision-of-school-education-right-of-child-and-duty-of-education-authority>

Right to be heard

Article 12 of the UNCRC outlines the right of all children to express their views, and have these views listened to and taken seriously when decisions are being made that affect them.

Equality

All children have the right not to be discriminated against, both in school and out of school. Under the Equality Act 2010¹⁰, all responsible bodies have a duty not to treat disabled pupils less favourably than their non-disabled peers. They must also make “reasonable adjustments” for disabled pupils to ensure they are not disadvantaged. This duty applies to all local authorities and their schools, and also to independent and grant-aided schools.

Wellbeing

The Scottish Government’s Getting it Right for Every Child framework (GIRFEC) is the national approach to improving the wellbeing of all children and young people. GIRFEC focuses on key areas of wellbeing, and aspires that all children should be: Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible, and Included.

Inclusion

The Standards in Scotland’s Schools etc. Act 2000¹¹ sets out the “presumption of mainstreaming” that all children must be educated in mainstream school settings, unless certain exemptions, which are expected to only arise exceptionally, are applied.

The Scottish Government has recently consulted on its guidance on the implementation of the presumption of mainstreaming policy, reiterating its commitment to mainstreaming as a “central pillar” of an inclusive approach to education. The draft new guidance sets out the key features of what should constitute an inclusive education; that all pupils should be present, participating, achieving and supported.

In 2017 Scotland’s Ten Year Strategy for the Learning Provision for Children and Young People with Complex Additional Support Needs 2017-2026 was published. Its aim is: *“...that by 2026 Scotland will be a world leader in relation to providing the highest quality education to children and young people with complex additional support needs. An outcome review in 2026 should be expected to evidence a well-developed history of proactive collaborative working between national government,*

¹⁰ Equality Act 2010: <http://www.legislation.gov.uk/ukpga/2010/15/contents>

¹¹ Standards in Scotland’s Schools etc. Act 2000 section 15: <https://www.legislation.gov.uk/asp/2000/6/section/15>

local authorities, independent providers (3rd Sector), national and international training providers (Universities, Education Scotland, SCEL etc).¹²

The Curriculum for Excellence¹³ sets out what children and young people should be learning in school, and how they should be taught. Its purpose is to provide a coherent and flexible education from age 3 to 18, that helps all pupils to become successful learners, confident individuals, responsible citizens and effective contributors. Under the Curriculum for Excellence, every pupil is entitled to experience personal support to enable them to gain as much as possible from the opportunities that school can provide. The curriculum is designed to be flexible, to make sure that all learners needs can be met.

The Scottish Government has funded the development of an Autism Toolbox¹⁴ to support the inclusion of autistic children in mainstream schools. It is a resource designed for teachers giving key information about autism, and advice and resources for supporting autistic pupils in the classroom.

In March 2018, the Scottish Government refreshed the Scottish Strategy for Autism's Outcomes and Priorities for 2018-21¹⁵ which contain commitments to *“build on education resources, such as the Autism Toolbox, to ensure teachers and the education workforce have access to resources designed to help them better support autistic children”* and *“work with universities who deliver teacher education to explore how we can increase awareness of autism in teacher education.”*

Attendance and exclusion

The Scottish Government has issued two key guidance documents on attendance and exclusions in Scottish schools, called 'Included, Engaged and Involved' parts 1 and 2. Part 1, published in 2007, deals with attendance and aims to encourage and promote good attendance for all pupils. It regards any kind of absence as disruptive to learning, regardless of its cause. It sets out a commitment to ensure that all children are included and supported to engage in and benefit from their education. The guidance explains how patterns of attendance and absence are often key indicators of the need for support.

Part 2 of 'Included, Engaged and Involved', which gives guidance on preventing and managing school exclusions, was most recently updated in 2017. This guidance sets out clearly that formal exclusion from school should only be used as a last resort, and with an aim of improving outcomes for the child or young person. It states that the wellbeing of the pupil should be the key consideration in all decisions, and that any exclusion should be used constructively to resolve any issues and make sure the right support is in place for the child.

¹² <https://www.gov.scot/Publications/2017/06/7935/9>

¹³ Information about the Curriculum for Excellence can be found on the Education Scotland website: [https://education.gov.scot/scottish-education-system/policy-for-scottish-education/Policy-drivers/CfE-\(building-from-the-statement-appendix-incl-btc1-5\)](https://education.gov.scot/scottish-education-system/policy-for-scottish-education/Policy-drivers/CfE-(building-from-the-statement-appendix-incl-btc1-5))

¹⁴ www.autismtoolbox.co.uk

¹⁵ The Scottish Strategy for Autism: Outcomes and Priorities 2018-2021: <https://www.gov.scot/Resource/0053/00533392.pdf>

As well as explaining the legal grounds for exclusion and the process that must be followed, the guidance is also clear about use of unlawful exclusions. Unlawful exclusions are sometimes referred to as ‘informal exclusions’ or ‘cooling-off periods’ and describe a situation where a child is sent home, but it is not formally recorded as an exclusion. The guidance states that this must not happen, and that all exclusions from school must be formally recorded.

The use of part-time timetables following an exclusion is briefly covered in this guidance, but neither part 1 or 2 of ‘Included, Engaged and Involved’ specifically talk about the use of reduced timetables for children with additional support needs. There is no specific entitlement to full time education in Scottish law, but it is implied by the right to an education that is directed to developing a child’s abilities to their *fullest* potential. It is also implied by the right to equality of opportunity, and for disabled children not to be treated less favourably than their non-disabled peers. The Education (Scotland) Act 2016¹⁶ gives Scottish Ministers the power to set in law a prescribed number of learning hours that all children will be entitled to. This part of the Act has yet to be implemented.

The most recent Scottish Government guidance on the education of children unable to attend school due to ill health¹⁷ states that if a child is unable to attend school due to ill-health, including mental health difficulties, local authorities have a duty to make alternative arrangements for their education “without undue delay”. A child’s right to education remains if they are unable to be physically present at school. The guidance does not specify a minimum number of hours of education or support a child should receive if they are not in school.

Support to learn

Regardless of the setting in which they are educated, all pupils who are educated by their local authority should be provided with the support they need to fully benefit from their school education. The Education (Additional Support for Learning) (Scotland) Act 2004, as amended¹⁸ (the ASL Act), states that:

“Every education authority must [...] in relation to each child and young person having additional support needs for whose school education the authority are responsible, make adequate and efficient provision for such additional support as is required by that child or young person.”

The ASL Act says that every child and young person with additional support needs should receive the support that they as an individual need to get the most out of their school education and reach their “fullest potential”. It recognises that barriers to learning can arise from a wide range of factors,

¹⁶ Education (Scotland) Act 2016 part 3, section 21: <http://www.legislation.gov.uk/asp/2016/8/section/21/enacted>

¹⁷ Guidance on the education of children unable to attend school due to ill health (Scottish Government, 2015): <https://www.gov.scot/Publications/2015/06/6846>

¹⁸ Education (Additional Support for Learning) (Scotland) Act 2004, as amended: <http://www.legislation.gov.uk/asp/2004/4/contents>

and that support may be needed for any length of time. The ASL Act applies to a child who requires support “for whatever reason”, and as such a child does not need to have a diagnosis to be entitled to receive the support they need at school. This means that children who are struggling at school who may be autistic, but have not yet been assessed or diagnosed, should still receive the support they need to learn.

The support that is provided for all children with additional support needs must be kept under review to ensure it is meeting their needs. The ASL Act sets out a framework for the planning and monitoring of support to help with fulfilling this responsibility. In early 2018, an amendment to the ASL Act gave children with additional support needs aged 12-15 many of the same rights as parents and young people (aged 16 and over) to be involved in decisions about the support they receive, and to challenge decisions that they do not agree with.

Detailed guidance to support schools and local authorities in implementing their statutory duties under the ASL Act is set out in the Supporting Children’s Learning Code of Practice¹⁹.

Involving parents

The vital role that parents play in children’s learning and development is recognised in the Scottish Schools (Parental Involvement) Act 2006²⁰. This act aims to make sure that parents are meaningfully involved in their children’s education.

This is also a key feature of the statutory guidance on the ASL Act, which sets out how parents should be involved in decisions about their children’s support. The Supporting Children’s Learning Code of Practice states that: *“Professionals need to involve parents and take account of their views on their child’s development and education at the earliest opportunity. Partnership with parents is, therefore, central to ensuring that children and young people with additional support needs benefit fully from school education.”*

¹⁹ Supporting Children’s Learning: Statutory Guidance on the Education (Additional Support for Learning) Scotland Act 2004 (as amended) Code of Practice (Third Edition) 2017: <https://www.gov.scot/Publications/2017/12/9598>

²⁰ Scottish Schools (Parental Involvement) Act 2006: <http://www.legislation.gov.uk/asp/2006/8/contents>

CHAPTER 3 - AUTISTIC PUPILS' SCHOOL EXPERIENCES

This chapter highlights the body of evidence supporting our concerns about the barriers faced by children with additional support needs, and particularly autistic pupils. We are keen that the findings from this report contribute to a better understanding of the challenges facing Scottish education, and the opportunities for improvement.

The Scottish Government's statistics on school exclusions and attendance²¹ show that the exclusion rate for pupils with additional support needs is almost five times higher than for those without additional support needs. In 2016-17, 4% of all exclusions were of autistic pupils²².

In mainstream schools, the attendance rate for pupils with additional support needs is 91.2%, compared with 94.1% for pupils without any additional support needs. The attendance rate for autistic pupils is 91.6%²³. 'Attendance' includes those who are participating in the programme of educational activities arranged by the school, such as those who are absent due to ill health but being provided with appropriate educational provision.

Education and Skills Committee report

In 2017, the Scottish Parliament's Education and Skills Committee published a report looking at the implementation of the additional support for learning legislative framework²⁴. This report concluded that *"the evidence points at a number of ways in which resources are not currently sufficient to support those with additional support needs in mainstream schools,"* and that this means that the policy of inclusion is making some children feel more excluded in mainstream schools than they would in a special school.

The report also specifically focuses on autism in one section, due to the volume of evidence they received in relation to autistic pupils. The report states that the autism evidence highlights *"the pressure on the education system in relation to this condition and also the danger that children with additional support needs like ASD can be perceived socially by children and parents as 'the problem'. It is undoubtedly the case from the evidence received that some disruptive behaviour is a direct result of being in an educational setting where children receive insufficient support due to insufficient resources"*.

²¹ Summary Statistics for Schools in Scotland, No. 8: 2017 Edition: <https://www.gov.scot/Publications/2017/12/3099>

²² School Exclusions 2016/17 dataset: <https://www.gov.scot/Topics/Statistics/Browse/School-Education/exclusiondatasets/exclusionsdataset2017>

²³ School Attendance and Absence in Scotland 2016/17 dataset: <https://www.gov.scot/Topics/Statistics/Browse/School-Education/AttendanceAbsenceDatasets/atttab2017>

²⁴ How is additional support for learning working in practice? (Scottish Parliament, 2017): http://www.parliament.scot/S5_Education/Reports/ASN_6th_Report_2017.pdf

IncludED in the Main?! Campaign

Enable Scotland's 'IncludED in the Main?!'²⁵ campaign has highlighted the difficult realities of the educational experiences of some children with learning disabilities, including autistic children. It questions whether the presumption of mainstreaming is working for these children in practice and brought to light some stark figures. For example, in their survey of more than 800 people (including parents, children and young people with learning disabilities and/or autism, and education professionals), 52% of the young people who responded said they did not feel happy with the support they were being given at school. One child aged seven told Enable: *"School is difficult for me. It is noisy and busy and there are bright lights. I don't understand the rules. I try to run away and hit out. I am often excluded."*

40% of parents and carers who responded to Enable's survey said their child had been unlawfully excluded from school, and 19% said this was happening on a weekly basis. A striking 98% of education professionals who responded said that they feel teacher training does not adequately prepare them for teaching young people with additional support needs, and 82% said they believed there is a shortage of classroom/pupil support assistants available to meet the needs of children with additional support needs educated in mainstream settings.

Numbers of specialist support staff

Data from the 2017 teacher census²⁶ shows that the number of teachers specialising in learning support and additional support needs (including English as an additional language) in 2017 was 2,835, a drop of 152 since 2016 and the lowest number of these teachers since 2010. Data shows an 18% decrease in the number of learning support and additional support needs teachers between 2010 and 2017. These figures point to an ongoing erosion of specialist teachers for children with additional support needs.

Presumption of mainstreaming consultation

The Scottish Government released a consultation on its guidance on the implementation of the presumption of mainstreaming in late 2017. The draft paper on which the consultation sought input reaffirms the Scottish Government's commitment to the policy and to inclusive education, while recognising the gap between legislation and policy and the everyday experiences of many. John Swinney, Deputy First Minister and Cabinet Secretary for Education and Skills, states in his ministerial foreword: *"We must improve the experience of inclusion for all pupils if we are to deliver on the promise of such an ambitious framework. Being present in a mainstream school should not be the primary marker of successful inclusion."*

²⁵ #IncludED in the Main?! – 22 steps on the journey to inclusion for every pupil who has a learning disability (Enable, 2017): <https://www.enable.org.uk/wp-content/uploads/2017/08/IncludED-in-the-Main-22-Steps-on-the-Journey-to-Inclusion.pdf>

²⁶ Teacher Census 2017: <https://www.gov.scot/Topics/Statistics/Browse/School-Education/teachcenssuppdata/TeaSup2017>

The consultation received hundreds of responses, and the analysis of these responses has recently been published²⁷. The analysis report states that most concerns raised were not about the vision and principles of the draft guidance, but that “current practice did not meet those aspirations”. It also describes how the most common concerns were around resources, including around sufficiency of teachers and support staff, access to specialist supports and provision, and the physical environment of schools. Many also reported a need for more training for support teachers and support staff.

Data from support services

The National Autistic Society’s Education Rights Service supported 377 families in 2017-18, with 57% of those families stating that they had concerns around the support that was being provided to their autistic child either by their school or the local education authority.

Enquire is funded by the Scottish Government and managed by Children in Scotland. Enquire provides advice and information about additional support for learning to children and young people, families and professionals. Enquire helpline data shows that autism is consistently the factor giving rise to additional support needs that the service receives the most enquiries about – amounting to 46% of all enquiries in 2017. As autistic children make up around 8% of all children with additional support needs, this clearly shows an overrepresentation of those seeking advice about issues relating to support for autistic children and young people. A significant number of enquiries are also received about autistic children who are out of school. In 2017, 22% of all enquiries to the service were about a child with additional support needs out of school for reasons other than formal exclusion. Of this number, 55% of the enquiries were about an autistic child.

Use of dispute resolution services

52% of all references to the Additional Support Needs Tribunal (ASNT) in 2016/17 were regarding an autistic child²⁸, with most of these being appeals against refused placing requests to specialist schools or units. In the previous three years, the number of references regarding autistic children represented between 65-68% of all references.

33% of the disability discrimination claims made to the ASNT in 2016/17 were regarding an autistic child.

This again shows an overrepresentation of disagreements about the right support and school placements for autistic pupils, when considering that the ASNT is open to all children with additional support needs, of which 8% are autistic.

²⁷ Excellence and Equity for All: Guidance on the Presumption of Mainstreaming - Analysis of consultation responses (Scottish Government, 2018): <https://www.gov.scot/Publications/2018/06/8071>

²⁸ Additional Support Needs Tribunals for Scotland 12th Annual Report (2017): <https://www.healthandeducationchamber.scot/sites/default/files/publications/19/ASNTS-12th-annual-report.pdf>

CHAPTER 4 - WHAT WE DID AND WHO WE SPOKE TO

In order to find out more about the realities of education for autistic children missing school in Scotland, we put together a survey aimed at parents and carers of autistic children who have had time out of school in the last two years. Our priority was to gain insight into the experiences of autistic children who have missed time from school, rather than to get a statistical picture of how much this is happening. We already know that this is a serious issue for many families – we wanted to find out what this looks like and what could be done to improve things for them.

The survey received 1,434 responses in total. 17 responses were removed as only the initial few questions had been answered. The number of responses equates to approximately 10% of autistic pupils in Scotland²⁹.

Understanding the findings

Results are of a self-selecting sample, and those parents that took part chose to do so, knowing that the survey was asking for experiences of children who had missed time from school. **We are not claiming that the results are representative of the experiences of all autistic children in Scotland.**

The results also do not offer a statistically accurate picture of the nature and extent of different types of absence across Scotland. What they do offer is important insight into the experiences of the families who responded.

We did not define “support” to those completing the survey. Due to the breadth of different supports available - with the huge range of personnel, technologies, strategies, communication aids, visual supports and so on that can be provided to children, it is impossible to provide an exhaustive list. We were interested to know what parents would recognise as support and left this open for this reason.

All questions in the survey were optional (except for the demographic information), and not every respondent answered every question. The percentages given in this report are calculated from the number of responses to each individual question. Corrections to the spelling and grammar in quotes have been made but no content has been changed.

²⁹ Pupil Census 2017: <https://www.gov.scot/Topics/Statistics/Browse/School-Education/dspupcensus/dspupcensus17>

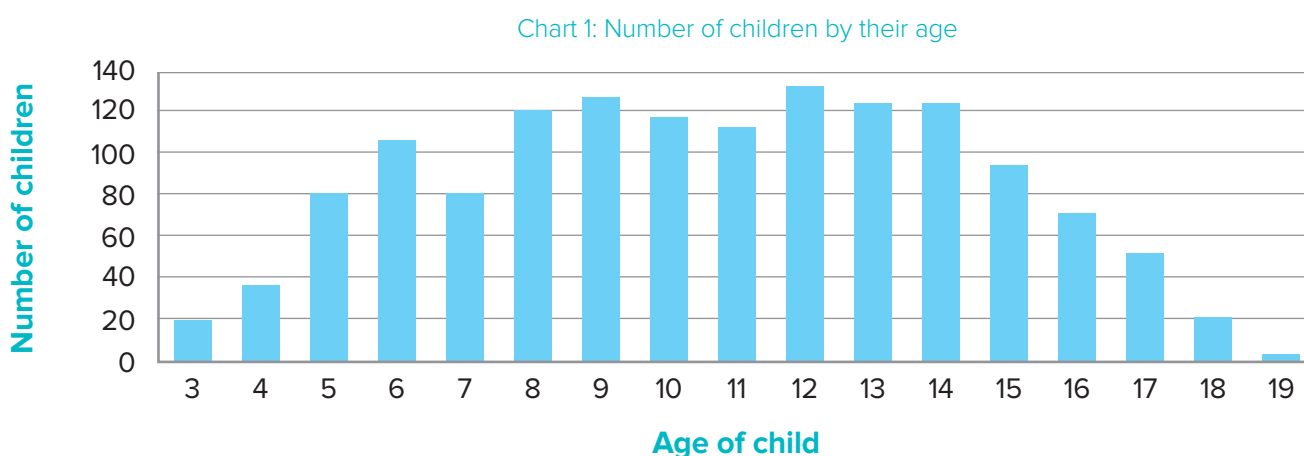
Local authority

Survey responses were received from every local authority in Scotland, with the highest number from those living in Glasgow and the lowest from the Western Isles. This does not necessarily represent the areas where children are missing school to the highest or lowest degree. The number of responses from each area may have been influenced by the number of existing parent support networks in different areas, where the survey was shared more often.

Age and stage

We received responses from families whose children were aged between 3 and 19 years old.

Chart 1 shows the spread of responses across ages.



4% (n=62) of children discussed in this report were in pre-school, 53% (n=752) in primary school, and 43% (n=603) were in secondary school.

Gender

The majority of children represented in this report were male (n=1069, 75%), with 24% (n=333) female, and 1% (n=9) with transgender or non-binary gender identities.

Type of education

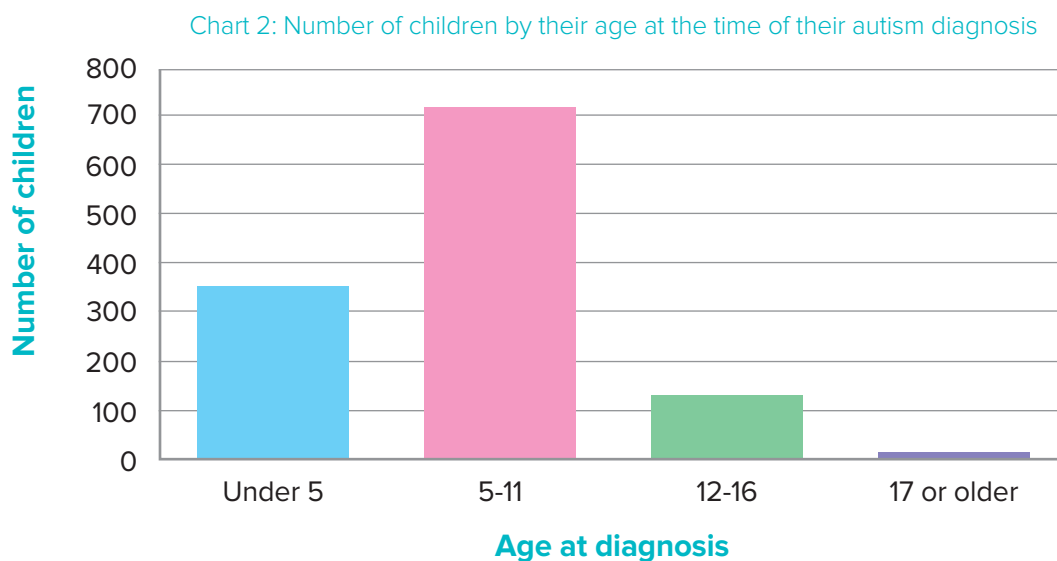
Respondents were asked what type of education their child was in at the time of filling out the survey. The largest group are those who attend mainstream schools (n=847, 59%), followed by bases or units attached to mainstream schools (n= 251, 18%), and special schools (n=119, 8%). Of those that selected 'Other', a majority described mainstream schooling with enhanced support provision.

Autism diagnosis

Respondents were asked whether their child currently has a formal diagnosis of autism. The majority (n=1248, 87%) had a diagnosis, 10% (n=140) were in the process of being assessed, and 3% (n=46) did not have a diagnosis.

We have included data for the children without a diagnosis in this report as respondents identified themselves as parents of an autistic child by completing the survey. We are aware that some people do not wish to pursue a formal autism diagnosis for their child for a range of reasons, including that they feel that self-identification is enough for their needs to be understood and met, or because they do not wish to engage with services.

Of those with a formal diagnosis, most (n=717, 59%) were diagnosed between the age of 5-11 years old, 29% (n=348) were younger than 5, and 12% (n=151) were older than 12 when they were diagnosed.



CHAPTER 5 - WHAT WE FOUND OUT

The research questions were designed to help understand more about the types of absence from school that autistic children are experiencing. The types of absence we asked about were: formal exclusion from school, unlawful exclusions, part-time timetables and children missing school for any reason other than common childhood illness.

“They were fond of telling us how supportive they were but never asked our child if he found their strategies supportive.”

Formal exclusions

We asked parents a set of questions about their child’s experience of formal exclusions. We described formal exclusion as when a parent has been told to keep their child at home for a set number of days, with a written explanation, and the exclusion has been formally recorded.

“They just did risk assessments and made him sign documents saying he would stop behaving in that manner. He was just 7 at the time and could barely write his name.”

185 parents (13%) told us that their child had been formally excluded from school. When the gender split of children represented in the survey is taken into consideration, boys (91%, n=168) were significantly more likely to be excluded than girls (9%, n=17). More of the exclusions took place at secondary schools (55%, n=102) than in primary schools (45%, n=83), and no exclusions from pre-schools were reported.

The highest number of exclusions were of children who were attending mainstream schools at the time of the exclusion (n=141, 76%). 14% (n=25) of children were excluded from bases or units attached to mainstream schools, 7% (n=13) were in a special school, and 1% (n=2) were in independent schools.

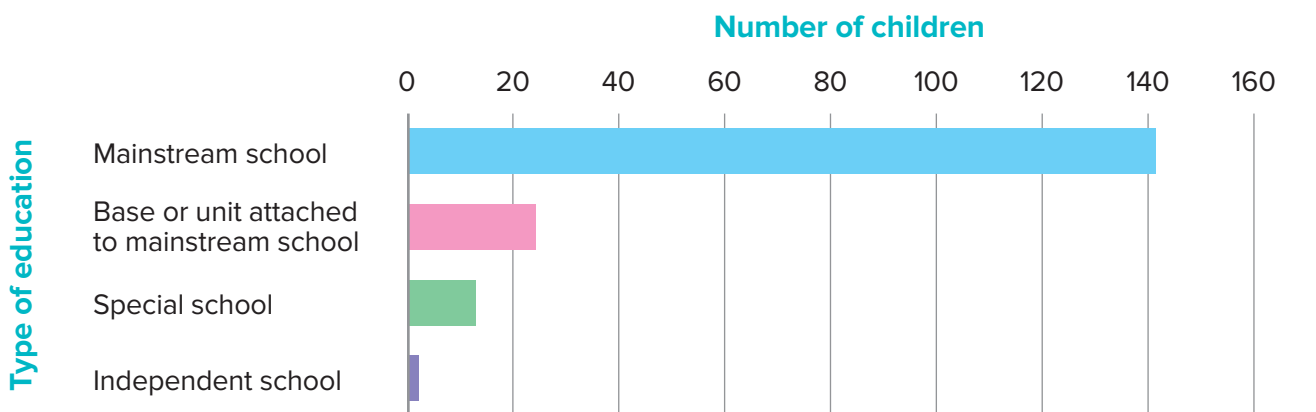


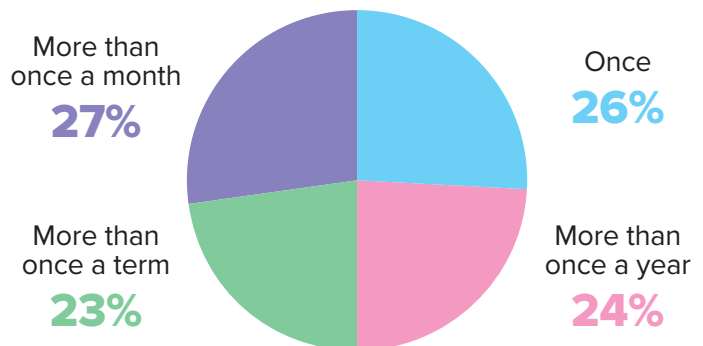
Chart 3: Number of children who have been formally excluded by the type of education they were in at the time of the exclusion

“This was for 2 days and he never returned to school after this other than to attend a meeting to put this on his school record and say he could come back but this is where he lost complete confidence [...] Given he was showing signs of getting on a wee bit better at school and given the constant struggle for him to go to school I pleaded they choose some other form of punishment if necessary as this wasn't appropriate for him given his previous situation. I could see that this was down to ignorance and not understanding how an autistic child thinks that he couldn't speak up for himself. Should never have happened, this decision destroyed him!”

The majority of respondents (n=137, 74%) told us that their child had been formally excluded on more than one occasion. For 27% (n=49), their child had been excluded more than once in a month.

Number of times child formally excluded

Chart 4: Number of times children have been formally excluded from school



When asked whether their child received support to catch up with school work during their time off school, 91% (n=165) of parents told us that they had not received any support with this.

“I've had a few meetings with the school trying to put things in place and its always the same “we don't have the resources.””

We also asked respondents whether their child's support needs had been discussed with them before they returned to school, as the Scottish Government's guidance on exclusions states that this should happen. For approximately half of parents, (n=89, 49%) this discussion did not take place.

“In the last 2 years my child has had 5 schools. He was excluded or asked to leave from 3 of them. [...] He got no support either when excluded or returning to schools it was left to us to fight for places or find suggestions. And left to us to support him. All whilst trying to maintain full time employment to support our family and try and establish some sort of normality for our children. It affected my son's mental health as he felt the rejections and sense of giving up and exclusion from every one of the schools.”

Unlawful exclusions

Sending a child home from school without formally excluding them is against the law – all exclusions must be formally recorded. This kind of exclusion is sometimes referred to as an ‘informal exclusion’ or ‘cooling-off period’, and guidance on the law is strong in its position that this must not happen. As they are not recorded, by nature there are no statistics available currently on the extent of the use of this practice. Anecdotally there is an awareness that it is happening regularly for some autistic children, and therefore we wanted to include this in the research.

“Anytime he became upset, refused to stay in the class I was called to collect him. This happened nearly every day.”

We described unlawful exclusions to respondents as when a child has been sent home from school or asked not to attend, without being formally excluded (e.g. school asking parents to pick up their child early). 37% (n=478) of parents who responded to this question told us that their child had been excluded in this way.

The results show a significant difference in gender, with boys (83%, n=393) more likely than girls (17%, n=81) to be unlawfully excluded. A similar number of children were unlawfully excluded from primary schools (49%, n=232) and secondary schools (47%, n=227), with a small number also occurring in pre-school settings (4%, n=19).

Most of the unlawful exclusions that parents reported to us took place in mainstream schools (78%, n=368). Most other instances of unlawful practice took place in settings where children were receiving some specialist input, either in a base or unit attached to a mainstream school (13%, n=60) or in a special school (6%, n=29) setting.

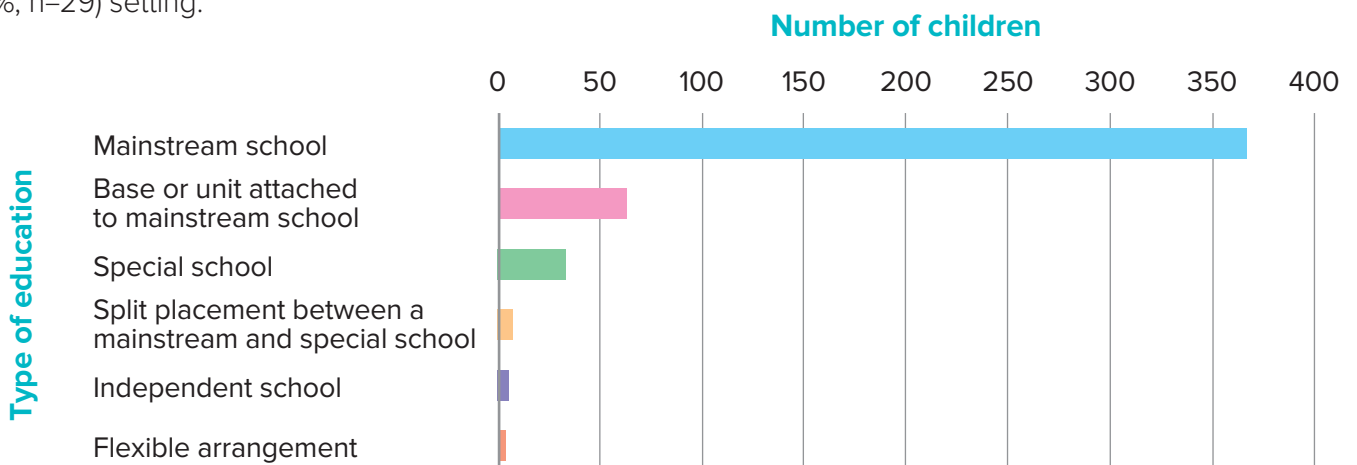


Chart 5: Number of children who have been unlawfully excluded by the type of education they were in at the time of the exclusion

“Yes, asked to pick him up early, lost count of phone calls for that one. Yes, was asked to keep him home on more than one occasion, they didn't have the staff or time, he was back to school but still struggling to go back into the classroom with peers. His sensory issues were not being recognised as sensory issues, they were actually being described as him being rude, not listening, not trying, I would explain to him what would be happening that day, he would go, and they would change things and he wouldn't cope. One occasion was for all these reasons. The other time was well in a nutshell they had a lot going on at school exams, transitions etc so no staff to support so they suggested a domestic package. Basically I teach my son from home!! I was still off work sick with stress at this time.”

“This happens regularly. If they don't have sufficient staffing levels, they can't support him, so we are asked that he stays at home.”

“Frequently threatened with exclusion if we did not come and take him away.”

When asked how many times their child had been sent home from school without it being treated as a formal exclusion, a majority of parents (85%, n=403) told us that this had happened more than once. For almost a quarter, this had happened multiple times per week (22%, n=105).

Number of times child unlawfully excluded

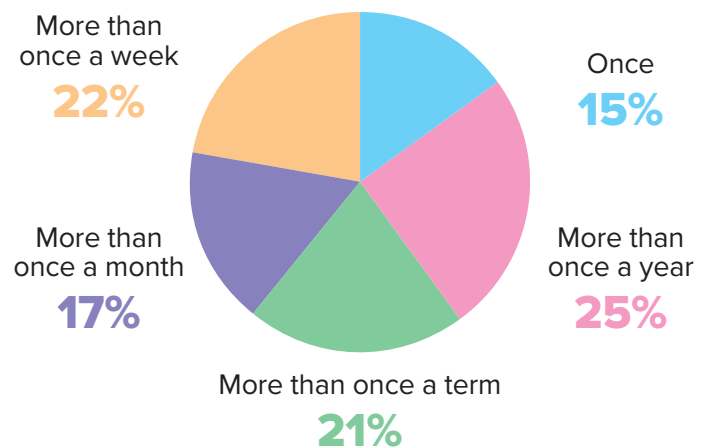


Chart 6: Number of times children have been unlawfully excluded from school

As with the other types of absence reported in this chapter, a large majority (91%, n=428) of children did not receive support to catch up with school work while they were absent.

“I was called around 2 to 3 times a week to collect him from school as they could not cope with him. This went on for around 2 years.”

“They call me every day nearly as they can't cope with him.”

“My child was not even in an hour in school, but school were phoning asking us to go pick him up.”

“I had to come and pick him up every day at 12 because they could not cope a full day with him, it was like that for 7 years.”

Part-time timetables

There can be circumstances when a part-time timetable for a particular child can be beneficial, and in their best interests at that time. For example, when recovering from an illness, or as a short-term measure until more or different support, or a suitable placement, can be put in place. One concern about the use of part-time timetables arises where a child has been placed on a reduced timetable as a way of managing their support needs, and/or for a prolonged period of time.

“We have complained and had several meetings, but nothing changes the daily crushing feeling that he is being failed and deserves better.”

31% (n=394) of parents who responded to the survey told us that their child had been placed on a part-time timetable in the last two years. In contrast to the other types of absence explored in this chapter, proportionally girls were 1.3 times more likely (based on an odds ratio) than boys to have been placed on a reduced timetable.

“The main class teacher and head teacher both agree the school can't offer enough for him to have a full timetable. This has gotten worse as therapies (music especially) have been withdrawn.”

Reduced timetables were much more likely to happen in secondary schools (63%, n=249) than in primary schools (35%, n=138). A small number (2%, n=7) of children who had been on part-time timetables were at pre-school age.

“I felt I had no choice. I had already had to resign from my job due to the amount of support I was giving the school and it seemed like the only way to prevent further distress to my child.”

Most of the instances of reduced timetables took place in mainstream schools (75%, n=304), with a significant minority taking place in bases or units attached to mainstream schools (16%, n=63) and special schools (6%, n=25), as shown in Chart 7.

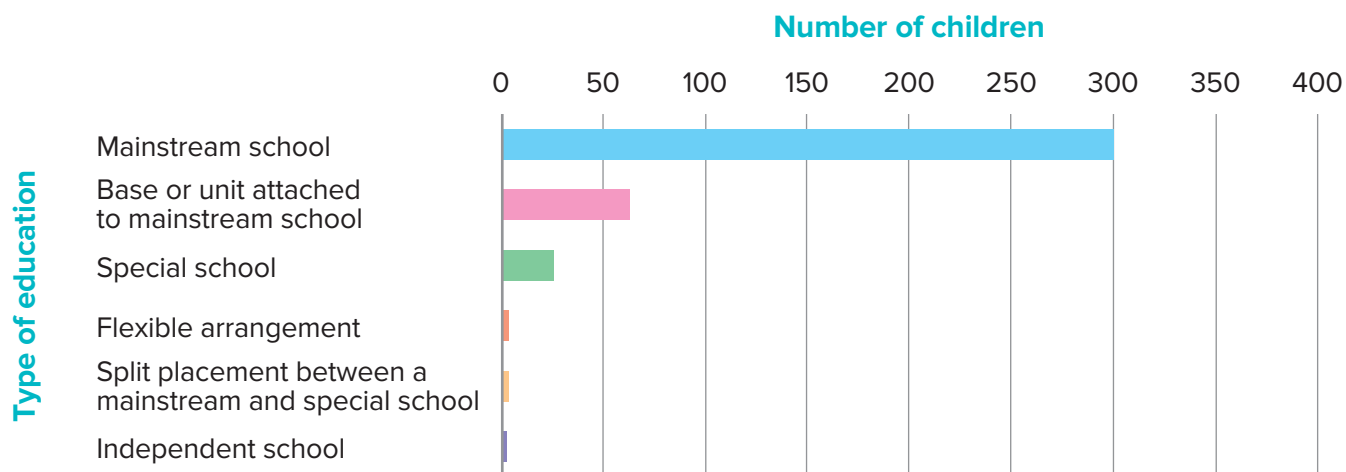


Chart 7: Number of children who have been placed on part-time timetables by the type of education they were in at the time

“For almost a year my son was on a part time timetable, the last 6 months was an hour a day.”

“School stated no funding for support and couldn’t keep my child or others safe without it.”

We asked parents who had suggested the part-time timetable, finding that in the majority of cases (68%, n=270), school staff had suggested it. We gave respondents the choice of selecting more than one option, in recognition of the fact that sometimes these decisions are joint or not from one source only. 25% (n=98) of parents told us that they themselves had suggested it, and 24% (n=94) said that other professionals (such as those from health or social work) had suggested it. 18% (n=72) selected ‘Other’ and left comments, with most of these indicating that it had been a joint agreement, and a few naming other people, such as educational psychologists, who had suggested it.

“Bank of classroom assistants was empty for 6+ months. Educational Psychologist then reduced his hours because no assistants were available for this huge period of time.”

“Was reduced to an hour a day! Over a year later we are still on a part time timetable. As parents we are unhappy with the situation. He is falling behind his peers massively.”

“She cannot cope with the stress of attending more than part time at present because the environment of the mainstream school is just not suitable however as she is intelligent she does not qualify for any different learning environment - it has been turned down. And there currently seems to be a complete lack of any adequate schooling provision for children like my daughter who has high functioning autism spectrum disorder but cannot cope with the busyness and noise and confusion of mainstream high school.”

“He has never had a full school day.”

83% of parents (n=242) told us that they gave their consent for their child to go on to a part-time timetable. We received some comments indicating that some parents felt that this was their only option. Others acknowledged that they were happy with the decision, as their child was having a difficult time at school and this lightened things for them. Others were unhappy with the arrangement and did not feel it was beneficial for their child.

“It was the only thing that would keep him going to school - it was agreed by all parties.”

“We did not agree to it. The headteacher said it would be best for the child. Little did I think a year later we would still be in the same position. It was awful for us as parents. The school reduced his timetable once the hospital suggested he may be on the spectrum.”

When asked whether their child had been placed on a reduced timetable on more than one occasion, 63% (n=248) of parents told us that they had.

“School became so stressful for him and after a lot of failed supports, I felt that was his only chance of getting some sort of education.”

“I felt pressured into accepting reduced timetable as they kept repeating how much they couldn't cope with my son.”

We wanted to understand the duration of part-time timetables experienced by autistic pupils. The findings on this are shown in Chart 8. The chart shows that the majority of children (55%, n=214) were on a reduced timetable for more than six months.

“My son had to drop subject after subject until he only had the bare minimum.”

“What choice did I have? Had I not then they would’ve excluded him. It’s supposed to be last resort exclusion but in our experience, it was first.”

“Rights are ignored constantly and consistently.”

How long children were on a part-time timetable

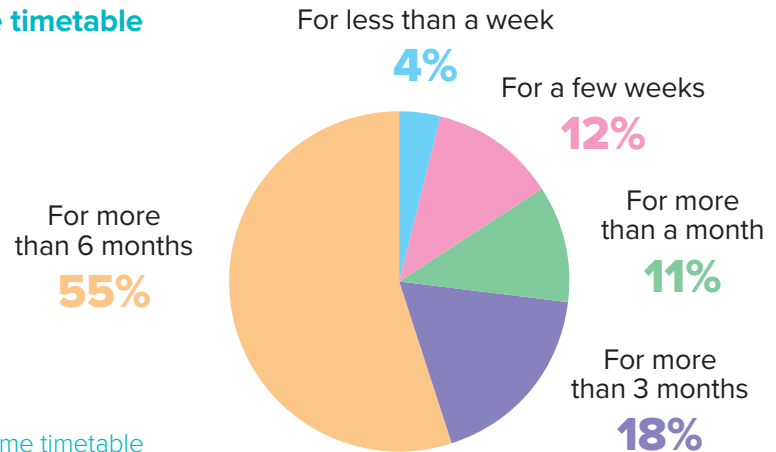


Chart 8: Period of time children were on a part-time timetable

We asked parents whether they were informed how long their child would be on a part-time timetable, and 80% (n=309) told us they were not. As has been the case for the other types of absence, a large majority of children were not supported to catch up with school work while they were absent (86%, n=327).

“With a part time one she feels anxious as she doesn't know what is going on in the lessons.”

“No but school said she was 'not very bright' so it didn't matter- I complained to the council.”

Time out of school for reasons other than common childhood illnesses

We felt it was important to capture types of absence other than the formal exclusions, unlawful exclusions, and use of part-time timetables. We wanted to understand more about some of the other reasons an autistic child might miss school that we have heard about from families through our own services, for example where a child is too anxious to attend, or where parents have kept their child off school because they do not feel they will be supported there.

71% of all respondents (n =1004) said that their child had missed school for reasons other than common childhood illness in the last two years. The split of this number by gender is very similar to the breakdown of all respondents to the survey, with 74% boys (n=743), 25% girls (n=251) and 1% transgender or non-binary gender identities (n=7). 3% (n=30) of children who have missed school for reasons other than common childhood illnesses were at pre-school. The numbers of children attending primary and secondary school were evenly split 49% (n=487).

“Anxiety, bullying, lack of proper consistent support, issues with inappropriate behaviour from other children, too many unknowns etc.”

We asked respondents what type of school their child was attending at the time of the absence. 79% (n=740) were in mainstream schools, 12% (n=110) were in bases or units attached to mainstream schools, 6% (n=59) were in special schools, and 3% (n=24) in other provisions.

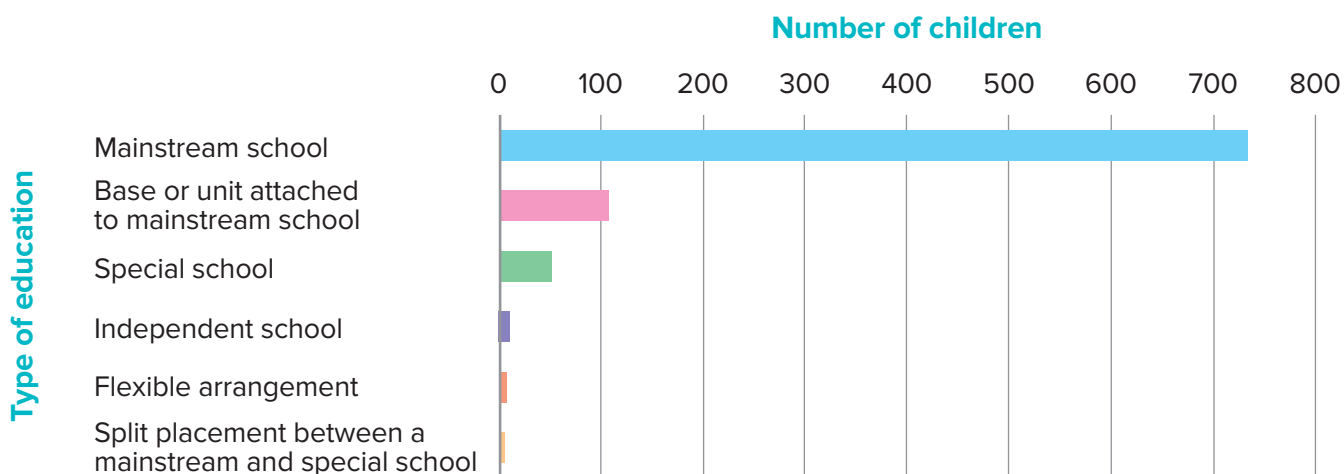


Chart 9: Number of children who have had time out of school for reasons other than common childhood illnesses by the type of education they were in at the time of the absence

When asked about their perceived reasons for their child’s absence, respondents were given a range of options and told to select all those that they felt applied. They were also given the opportunity to list any other reasons they felt were behind their child missing school. Some responses mentioned incidents that could be considered unlawful exclusions. The responses to this question can be seen in Chart 10.

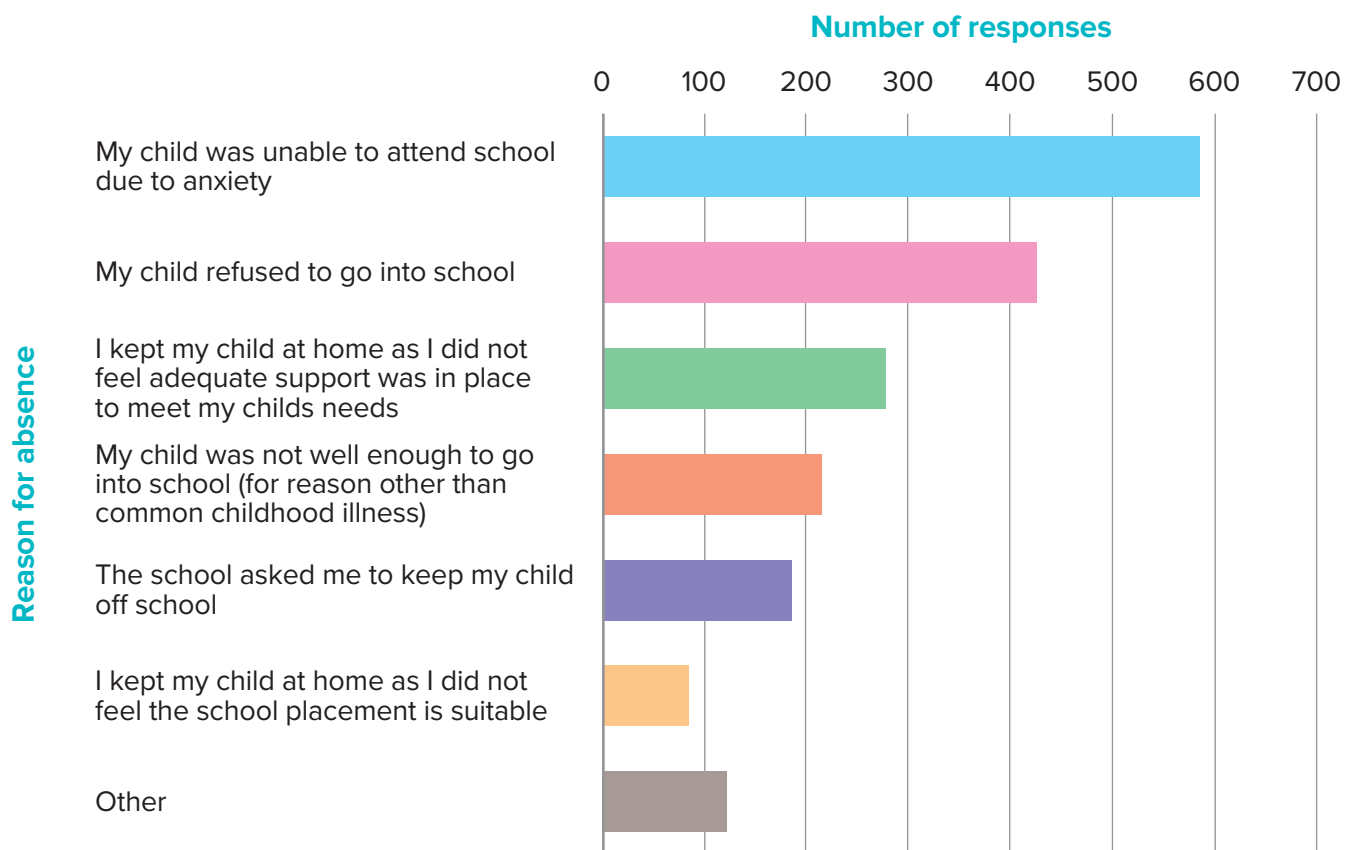


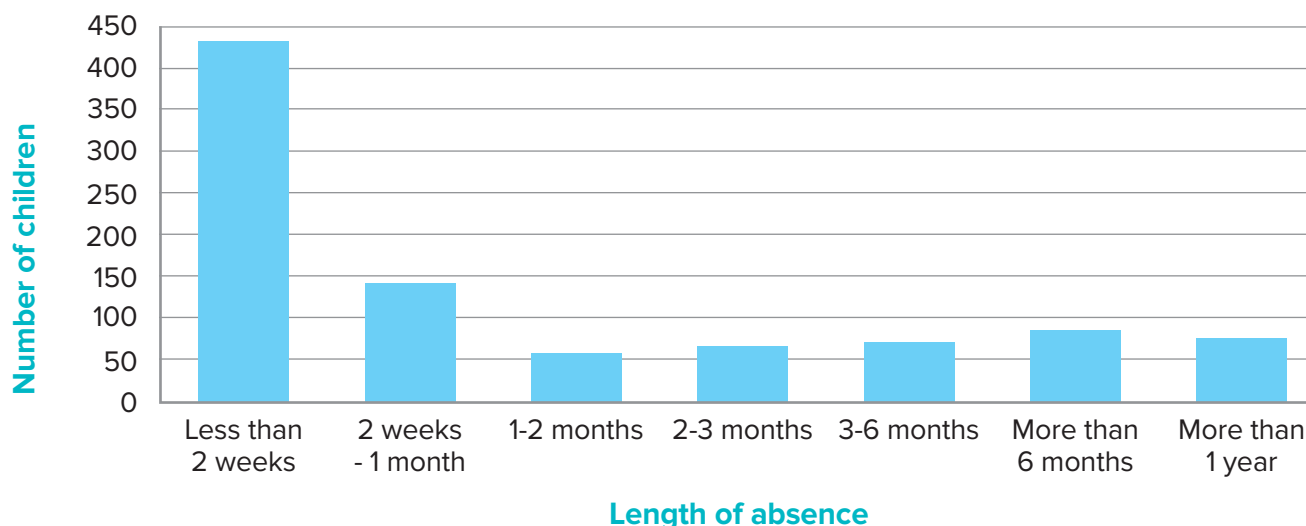
Chart 10: Reasons given for a child being out of school for reasons other than common childhood illnesses

The most commonly given reason for children’s absence was that they were unable to attend due to anxiety (n=579, 63%), with the second most often given reason being children refusing to go in to school (n=433, 47%). A high number of respondents felt that there was not adequate support (n=277, 30%), or a suitable placement (n=83, 9%), for their child and as such felt they needed to keep their child at home.

“The thought of school can create anxiety and a violent meltdown. Can’t enjoy the weekend because she is dreading the end. In general school is good but the smallest thing - teacher off ill, issue with friend causes problems. She also struggles academically and some subjects (maths) make her feel stupid (her words) and reinforce to her that she has a disability.”

The majority of these absences were for less than two weeks (n=431, 47%), with 15% (n=141) absent for between two weeks and one month. A significant minority of children missed school for a prolonged period, with 9% (n=83) absent for over six months, and 8% (n=77) absent for more than a year. The full range of periods of absence can be seen in Chart 11.

Chart 11: Length of absence from school for children who have been out of school for reasons other than common childhood illness



Approximately a third (n=315, 34%) of the children who had missed time from school had experienced more than one absence of more than two weeks during the last two years.

“One year of intermittent absences, not just one continuous one. This has led to school refusal. The school moved him into a composite class but not gradually and it caused him anxiety. Told to just get him to school and they’d deal with it from there. Still ongoing issues. Support very lacking.”

“The school has on the whole been very supportive, however it has been very difficult to access a suitable environment in mainstream environment which is quiet, calm and predictable enough, for it not to be an incredibly stressful experience. Out of the mainstream classroom environment it has been difficult to get any actual teaching input for new material.”

“After the shorter absences there was no support which just made his anxiety worse leading to more absences.”

We asked parents about the support their children had received to catch up with school work while they were absent, giving examples such as school work being sent home, or home tutoring. 82% (n=753) of parents said that their children had not received such support to catch up with their work.

When asked about support to help their child return to school, 55% (n=503) told us that their child did not receive any support to return, 30% (n=279) were supported with the return, and 15% (n=135) said that this kind of support had not been needed, as shown in Chart 12.

Support to return to school

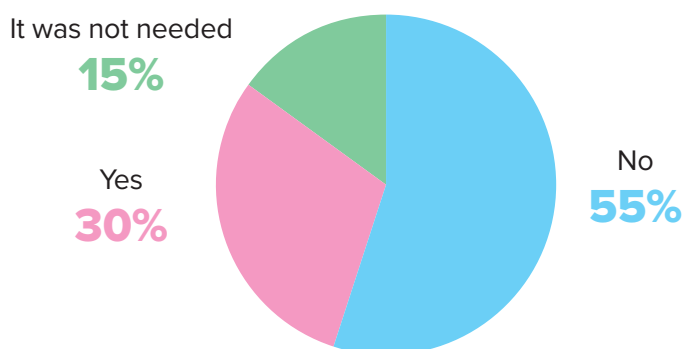


Chart 12: Percentage of children given support to return to school following a period out of school for reasons other than common childhood illnesses

“I feared for my daughter’s safety and mental health while at school.”

“High school was a tipping point. Triggered a mental health crisis and he has never been at high school for a full week ever.”

“I was told they had no suitable placement for my son. He had tried mainstream high school but was unable to attend because of extreme anxiety. I was offered a special school but was told that academically this would not provide a suitable level of education for my son who is high functioning and clever.”

“My son was refused enhanced provision and made to start mainstream at our local primary school. He only managed 13 days before he arrived home had an 8-hour meltdown and couldn't return. The school staff treated him badly e.g. allowing him to change for p.e. with the whole class knowing he was wearing pull ups and no one asking if he needed to go to the toilet or needed changed. He was given no support whatsoever as the head teacher of the school said he was intelligent so couldn't be autistic and didn't require any assistance.”

“He spent all of his primary education in a corridor and got sick of being told off so refused to go.”

“He also had great anxiety with the teachers not understanding autism and treating him like a bad child when overwhelmed. He was at the stage of saying it would be easier for everyone if he was dead.”

“Initial school refusal in P7 for a few weeks at time, twice. Then two weeks attendance at mainstream high school then refusal for 6 months, and now, two further school placements later, no school at all since June 2016.”

“The school said there were no teachers or support staff that wanted to work with him.”

“The school were supposed to provide work in line with what the class were doing but repeatedly failed to do so and the little that was provided was woefully inadequate and inappropriate.”

“I’ve been told it’s in his best interest to keep my son off during activities i.e. sports day, school plays, school trips unless I’m willing to come in and support him myself.”

“I was told to keep my son off because of others bullying him, until they sorted out the other kids!”

Multiple absences

As well as understanding the experiences of those who had experienced each of these types of absence, we also wanted to know whether there were children who were experiencing more than one, or even all, of these types of absence.

50% (n=714) of parents told us that their child had experienced more than one of these types of absence. Of this number, 7% (n=101) told us that their children had experienced all four of the kinds of absence described in this report.

Impact on children

We asked parents to provide information about the impact being off school had on their child by asking an open-ended question, giving them the opportunity to explain the impact in their own words.

Responses to this section were striking with 833 responses provided. 85 responses used language such as “no impact”, “none”, or “not applicable”, so the remaining 748 responses are discussed below.

Many parents mentioned more than one effect on their child.

Chart 13 shows the themes raised in parental comments about the impact that missing school had on their child.

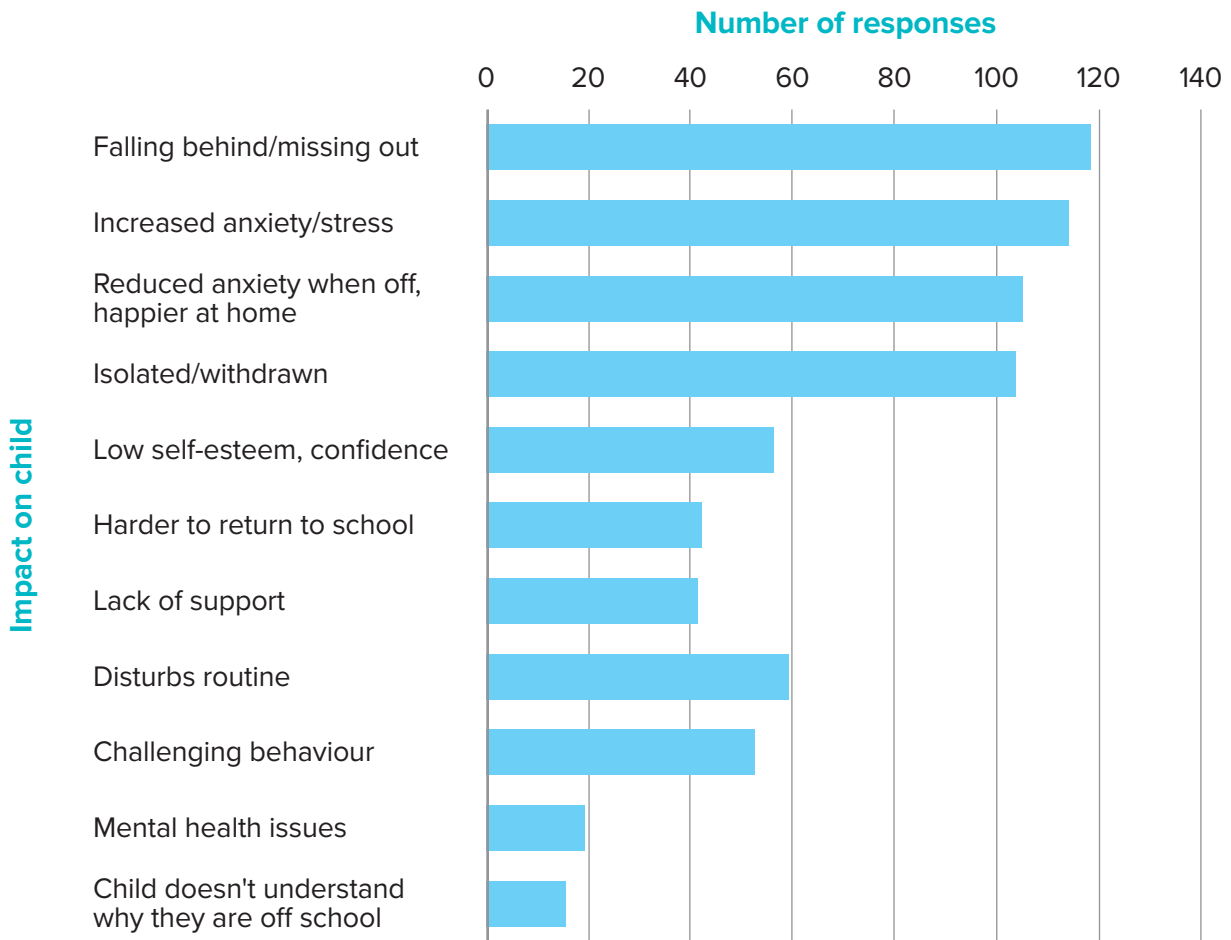


Chart 13: Main issues raised in parents' comments on the impact that being out of school had on their child

Pre-school

20 parents of pre-school children responded to this question. 40% of respondents (n = 8) felt that missing preschool or being unable to attend disrupted their child's routine. "Challenging" behaviour at home and nursery, falling behind peers and the impact on parents of having their child at home were also raised as issues.

"He likes routine. He gets upset because I am collecting him early."

"Disturbed his set routine. So was difficult at home, his behaviour was really challenging."

"Missed out on what else is going on. Excluded from trips away as not toilet trained."

Primary school

356 parents of primary school aged children provided information on the impact missing school had on their children.

Two of the most frequently mentioned impacts on children that parents described related to their child's anxiety and stress levels, together accounting for 31% of comments (n=109).

Of particular note is how many responses mentioned reduced anxiety and stress when off school (18%, n=65), indicating that parents thought their children were happier or felt safer at home. Parents cited being away from the difficulties children encountered at school as the main reason for this.

"My son finds it difficult going to school and then being told not to come to school. It makes him very stressed"

"If my son is off school for any reason then there is huge anxiety in return and this can impact for a while. He can become very unsettled."

"Made him anxious as he hates falling behind - upset at not being allowed to go to school."

"My child had been part time on and off since 2016 and it's still ongoing. He does get upset when having to leave school knowing his friends are still at school."

Many comments mentioned lack of support in school making school difficult for their children. Particular issues mentioned include lack of funding, unsuitable placements or lack of skills or knowledge to support a child.

“The school not supporting my child has been the main cause of school refusal. She is happy not to go to school. School itself is making her physically ill.”

“My child has no connection with her school placement, given that it is a split placement it means she deals with short term transitions on a daily basis. She has zero continuity of education and after nearly 5 months of school still has no education plan in place.”

“My son has become disaffected many times over the last 5 years. He thinks he is stupid as a result of no support for 4 years to allow him alternative strategies and approaches to his learning. Each time he is absent I build him back up to return to school but then nothing changes, and he gets angry and frustrated.”

Some parents had chosen to home educate as attending school had become too stressful for their child.

“My child is happier, more relaxed and more confident now she is being home educated. She did not receive any additional support in school and was behind educationally when I deregistered her.”

“Being off school eradicated my son’s anxiety. It helped him to not be educated at a school.”

A significant concern for parents was the impact missing school had on their child’s learning.

“My daughter is very behind on her work and is in P6 working at P3 level due to her 8 months off school. We ended up moving schools which has helped her progress dramatically. When she started there in P5 she was on P1 work.”

“He’s content and feels safe at home but he’s clearly missing out on education, social life and achievements in key areas. He’s had mental health issues to cope with, extremely agitated, horrendous sleep patterns not helped by a lack of routine. He missed out on his P4 trips to the swimming pool for lessons, something he’d have loved as he loves the pool.”

Another common worry for parents of primary school pupils was the impact being in and out of school had on their children's routine, highlighting that some autistic children can struggle with any form of change.

“She struggles with being off school as she needs stability and routine every day and she goes into meltdown mode if this changes.”

“When off school, it affects his routine and he becomes distressed by hitting himself and not sleeping.”

Parents expressed real concern about how isolated their children had become, highlighting in particular the impact this had on their children's confidence and ability to make and retain friendships and take part in other social activities.

Some parents felt their child being out of school led to feelings of mistrust of teachers and school staff and in some cases of all adults.

“My child became so withdrawn due to the amount of time away from school, albeit this is in turn due to his anxiety, he lost friendships, gave up on clubs that he was excelling at, and is still unable to return to any clubs. He is so scared of the world and people before he was outgoing and adventurous. It breaks my heart to see him now and at a loss for how best to help him to be that adventurous boy again.”

“Became very isolated. Anxiety level and therefore behaviour highly increased due to change in routine and lack of structure, very withdrawn and depressed.”

“He became reclusive, he lost confidence, he was very angry. He hated the school and everyone in it except the new deputy headteacher. He lost interest in the things he had once enjoyed.”

“He had no peer relationships. He has been out of school since half way through P2 and time has only been increased since he started P6 due to getting an education solicitor involved. Emotionally and mentally he has suffered. He wanted to go to school.”

Secondary school

380 responses were received from parents of secondary school pupils.

The issues raised by secondary school parents are similar to those raised by primary school pupils with some noticeable differences. While anxiety still remains a significant concern, falling behind or missing out on school work was the most pressing concern for many of the parents.

“Massive educational regression. She isn't receiving an education. She basically just sits in the quiet room or nurture room the whole school day.”

“Huge impact, she really struggled with not being able to do National 5s at same time as peers as a result of missing so much schooling.”

“Falling behind with work, difficulty integrating with peers, missing transition activities. Gaps in his learning. Impacted his self-esteem. Doesn't feel valued or included.”

“My child has missed the full first year transition from primary to high school... he's missed out on first year work and socialisation with peers! Very worrying.”

For many autistic children secondary school appears to be a stressful experience and missing school and falling behind with work can lead to additional negative feelings.

“In her 1 and a half years of secondary school she has only had the first 5 months of education. She has no social circle. She has very high anxiety surrounding school.”

“She became more depressed and anxious and no-one asked about her or cared about her.”

“Friendships that have been awkwardly fostered are forgotten by the time they go back, which causes more anxiety and depression.”

“The anxiety levels have increased due to the length of time she has been off. She's become withdrawn.”

Many secondary school parents responded that due to the stress and anxiety associated with attending school, their children were actually happier when they did not have to attend school, though this was mentioned less frequently by secondary school parents than by parents of primary school pupils.

“Home is my daughter’s safe place, so she prefers being at home.”

“Being off made her less anxious because she did not have to face the bullies or staff, she missed lots of work so fell behind. Made it much harder to get her to return.”

“At first she was happy to be away from an environment that had made her so unhappy. I think in time she wished that she could have fitted in and been like other children. She was in emotional and psychological distress for a while, about a year, but now she is OK, and has settled into a stable routine, which is the most important thing in this stage of her development.”

Some parents reported that their child needs time away from school to cope with attending. Other parents have made the decision to remove their child from school completely to resolve issues relating to stress and anxiety.

“The breathing space helped her calm down and so did the knowledge that I would not force her to go every single day if she was not able to do so.”

“It was the best decision we took to remove him from education. He wasn't coping with the work, he wasn't getting any support, his medical needs were not being met which was neglect and he was badly bullied. His mental state became a lot better during his time out of education.”

Similar to primary school parents, secondary school parents were concerned about their child becoming isolated and withdrawn from their peers when they are not in school. This is coupled with concerns that their child’s self-esteem and confidence are being damaged both by the experience of attending school without the right support and because they are missing school.

“Daughter has become more withdrawn and even less able to cope in social situations due to her anxieties worsening the longer she spends out of school.”

“Does not feel understood or supported. Does not feel listened to. Feels like she is missing out on things. Low self-esteem and confidence in addition to her anxiety.”

“She has become isolated and increasingly reluctant to socialise. She has become much more difficult to motivate in all other activities.”

“She became more recluse in her bedroom. Lost interest in friends or learning especially as she knew missed work and stressed about teachers understanding her.”

Impact on parents and families

Responses to the survey shine a light on the impact a child being out of school can have on family life. 779 responses were received to the question “Can you tell us the impact (if any) that your child being off school has had on you and the rest of your family?.” Chart 14 shows the main issues for families.

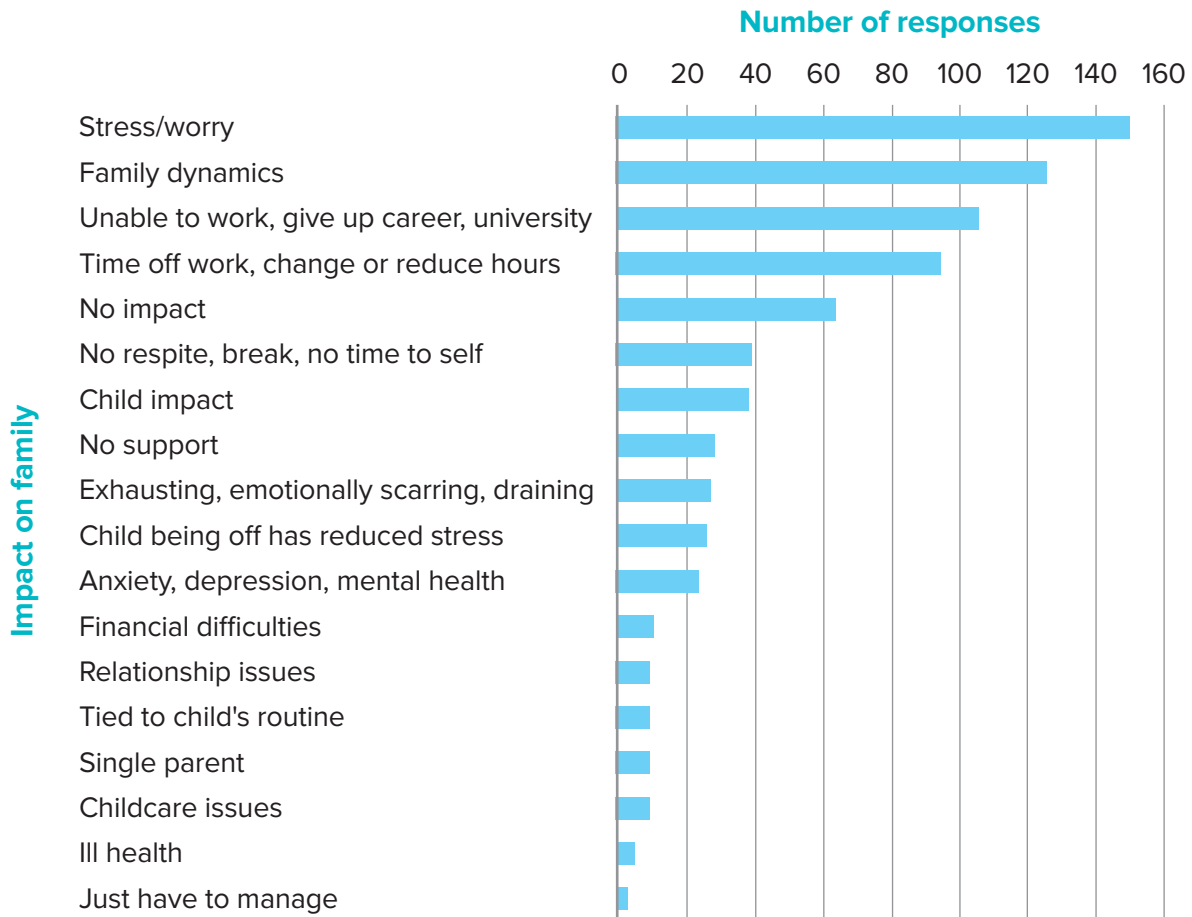


Chart 14: Main issues raised in parents' comments on the impact of their child being out of school on them and their family

Impact on parental mental health and wellbeing

The most frequently mentioned impact on families was stress and worry. Many parents mentioned the negative impact on their own mental health of worrying about their child.

“The whole situation has caused me major stress and anxiety and feeling depressed. My other children have suffered.”

“It increased our anxiety as parents because no one involved with our son had any idea what to do for a lengthy period of time.”

“My son is with me all the time. My own mental health is being badly affected as is my physical health.”

“He didn't have any routine because we didn't know when school would phone me to pick him up. it caused us a huge amount of stress worrying how behind he is.”

“It caused us distress too, because we were led to believe my daughter would receive adequate support, but like when she attended primary school, this was not the case. At first, we were upset, and felt let down again.”

“It has had a very negative impact on my mental health. Things are improving now, and I am learning to cope with the changed circumstances. My work life has been severely affected. I am self-employed and if teaching my daughter, I cannot work.”

Impact on parents' working lives

Parents reported additional stress from worrying about missing work when they had to pick up their child from school or stay at home to look after them. Parents also highlighted their reliance on relatives to enable them to continue to work.

“Had to plan our working hours around his reduced timetable.”

“I have had to take a leave of absence from my work to accommodate my child at home, it adds enormous pressure and stress on the whole family as we have lost structure and daily routine.”

“Very difficult to manage. I and my partner have had to take unpaid leave from work to look after him at home.”

“I have had to leave my job and if I'm at college and they phone I have to leave and pick him up. Because of this my mum doesn't go out so that I can go back to college and he stays with her.”

“Makes it hard to get to work when I'm not sure if I can get him to school.”

For many parents who responded to the survey, the impact of having to be available to look after their child during the day resulted in them not being able to work or being forced to give up employment. Parents highlighted the financial impact on their families of not being able to take up a job or training or reducing working hours. For some parents, their child being off school meant losing what was in some cases their only source of income in order to care for their child during the school day.

“Had to make adjustments to my job and reduce working hours, serious financial repercussions and not exploring career progression. Husband also had to change employment.”

“Struggle for child care. Loss of earnings. Stress. Single parent family.”

“I have had to miss work (unpaid leave) so reduced income.”

“Devastating. I have had to take two months off work to care for him. When he was on part time timetable I had to reduce working hours and I'm a single parent with another child.”

“As I am currently self-employed it has meant that I have been unable to work and earn any money whilst he's been off school. So, the impact is financial mostly.”

“I have lost my job, am on anti-depression medication, cannot find employment as I never know if she'll be at school or if I will get a call to collect her. I cannot imagine how bad it will be at high school. I can't get a job until she's older and we face losing our home.”

“I have severe anxiety caused by the stress of him not going to school. I can't go out to work as I need to be at home for him. This causes us extreme financial pressure.”

Impact on wider family

The impact of having children off school on family dynamics featured heavily in responses from parents. Concerns related to the impact of the stress involved on parents' relationships and wider impact on other children in the family.

Parents reported feeling exhausted and emotionally scarred and worried about their own mental wellbeing. Feelings of isolation and depression were also frequently mentioned.

“My family has been seriously affected. I’m exhausted as I have had my child with me every day and every night for over 5 months now. Two other children are affected and think it’s unfair that my daughter gets me to herself every day. Strain on relationship also.”

“It has put great strain on our family, with myself having to take several weeks off of work. I also have to take time off of work to support my child with school trips and school activities e.g. sports day. This has made me feel ostracised and extremely embarrassed. Affecting my mental health and our family group.”

“I can't begin to describe how the effect ripples through the family. Devastating effect.”

“Days off work, sibling has become a young carer.”

“I can't go out and spend most of the time in house.”

“I feel like a prisoner in my own home and my other two sons are missing out on family days out as myself and my son who has autism spectrum disorder have to stay home.”

What would make the difference?

We wanted to find out what the parents who responded to the survey felt could have made a difference for their child. We gave them a list of options to select as many as they wanted from, and also gave them an opportunity to make any other suggestions. We received 1017 responses to this question. 8% of respondents (n=80) did not feel that any of the suggestions would have made a difference for their child, and 224 respondents left comments about their suggestions. Chart 15 shows the responses to the question.

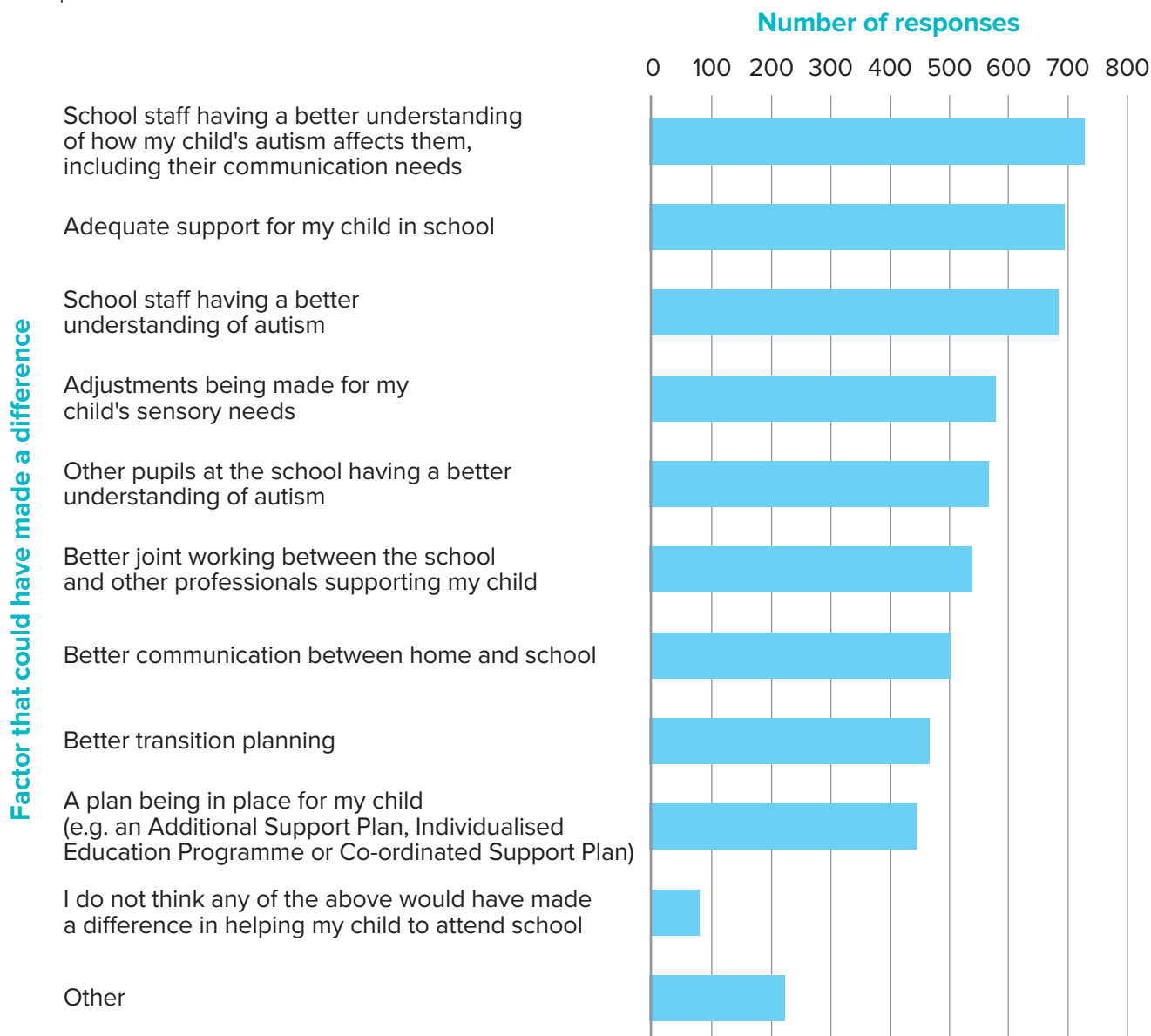


Chart 15: Factors that parents felt could have made a difference in helping their child to attend school

Understanding of autism

The most often selected answer was school staff having a better understanding of how their child's autism affects them, including their communication needs, with 72% (n=730) of parents feeling that this could have helped their child. This shows the need for an individualised approach for each child.

A better general understanding of autism was also felt to be important, with 68% (n=688) of parents feeling that school staff should have a better understanding of autism, and 56% (n=567) feeling that other pupils at the school should have a better understanding of autism.

“There are not enough specialist staff to deal with autistic children. Some children can only learn when they have staff who understand how to get the best from them and where they are not expected to look after other pupils at the same time.”

“Understanding and education for all involved in teaching and better education for children from an early age about autism and what it means and not just the 5-year-old boy who can't speak story, the teenager who can't go outside story, all the stories need told and understood.”

“The pupil support assistant (his 1-1 support) also fully admitted she wasn't qualified enough to aid his needs.”

“Teachers need to look for reasons behind behaviour not just see a young person being disruptive.”

“Staff training needs to be meaningful & proactive, not having a one size fits all attitude, some of the least experienced staff can be the most empathetic and proactive.”

Support at school

Many parents (68%, n=694) felt that if their child had adequate support in place, this would have helped them to attend school. 57% (n=578) also felt that adjustments needed to be made for their child's sensory needs. Given the legal requirement to both provide “adequate and efficient” support to each child with additional support needs, and to make reasonable adjustments for disabled children, it is concerning that such a high proportion of these parents did not feel these things had happened for their children.

“She wanted to be at school with her peers but couldn't overcome the sensory aspects/ transitions of moving around the building all day.”

“Total lack of support let my child down. Lack of communication to us when his agreed support was cut all had a devastating effect on my son which eventually resulted in him being asked to leave school.”

“My son is academically able and doesn't have a peer group in the special schools for severe and complex learning difficulties, but he's unable to cope in a 1000 pupil mainstream school. He's left in the middle with no provision.”

“If a safe and quiet place was available earlier in school this would have reduced the hours away from school.”

Communication

Half of the parents who responded (50%, n=504) told us that they felt that better communication between home and school would have helped their child's attendance. Better joint working between schools and other professionals was also felt to be important, with 53% of parents (n=543) saying they thought this could have made a difference.

“Communication is both the barrier and the key.”

“A single point of contact for my child. Someone who was willing and able to form a strong bond with him.”

“School did not listen to our concerns at all. We had to initiate all action. Huge lack of understanding & empathy towards autistic children & their families.”

“Staff working with parents in partnership, providing reasonable adjustments, making child feel valued, using technology to provide access to missed work, and allowing to work in a safe place. Better communication between all staff and understanding of the accumulative effects.”

Planning

44% of parents (n=447) told us that they felt that a plan being in place for their child would have made a difference for them, and 46% (n=465) thought better transition planning would have helped.

“It would have been easier had the primary school listened to our concerns. Then the transition would have been better.”

“All the information given about my child at the multi agency action planning meetings during her transition period to secondary school to have actually been taken account of instead of waiting to see how she sank or swam. The school is working very well with us now, but the damage has been done.”

It's important to consider the impact of autistic children missing school against the Scottish Government's ambitions, including the commitment to "excellence and equity" for all children and to ensuring that children's wellbeing is at the heart of any decisions made about their lives.

This report illustrates that a significant number of autistic children are being failed by the education system. They are not being given the same opportunities as other children to achieve or offered the support they need to enable them to attend and get the most from school.

Prevalence of the issues

Responses were received from every local authority area in Scotland, indicating that the issues are not unique to a handful of areas, but occurring across the country. Issues relating to autistic children missing school also seem to be affecting children of all ages, though there are some differences between different types of absence in whether they occurred more in primary or secondary schools. The number of children out of school for other reasons other than common childhood illnesses were at the same level in primary and secondary schools, unlawful exclusions were slightly more likely in primary schools, and formal exclusions and part-time timetables were much more likely to occur in secondary schools in our findings.

Many of the comments received from parents describe the particular challenges facing their children in secondary schools, such as the size, level of noise and sensory stimulation, number of transitions across the school day and increased social pressure. Some parents told us that they feel there is no suitable placement for their child when they reach secondary school age, particularly for those who are academically able but find it difficult to manage in such a busy school environment.

Some of the children represented in the survey are of pre-school age, showing that for some, difficulties are arising right from the point of entry into the education system.

Gender differences

In terms of gender, there were not any significant differences for those experiencing time out of school for any reason other than common childhood illness, but there were some interesting differences for the other types of absence. Boys were more likely than girls to experience formal exclusions and unlawful exclusions, and girls were more likely to be placed on part-time timetables. It is increasingly recognised that there are gender differences in the way that autism can present itself³⁰. It would be interesting to look further into these findings and the different ways in which autistic children of different genders are experiencing issues at school, particularly with regard to the strategies that are used when they are struggling and how their behaviour is interpreted.

³⁰ Kirkovski, M., Enticott, P. G., & Fitzgerald, P. B. (2013). A review of the role of female gender in autism spectrum disorders. *Journal of autism and developmental disorders*, 43(11), 2584-2603

Type of education

Across all types of absence, the majority of issues seemed to be arising in mainstream schools, indicating a particular need for action to be taken in mainstream settings to improve the experiences of inclusion for autistic children. However, all types of absence reported on also occurred in settings where children are receiving specialist input, such as in a base or unit attached to a mainstream school, or in a special school.

It is interesting to note that 37 of the children represented in the survey are now being educated at home, with their parents having taken on responsibility for their education. It is not known whether their child's experiences of missing out on their education impacted on this decision, but some of the comments received suggest that this is the case for at least a few families.

Autism diagnosis

Many parents told us that their child had been diagnosed with autism at an early age - results from the survey suggest 722 children were diagnosed before the age of 8. It is concerning to note that having their needs recognised early does not seem to have been a protective factor for these children in experiencing issues at school.

Length of absences

Some of the absences reported were for a relatively short period of time or may have only occurred once. While this may seem less likely to have an impact than some of the prolonged and frequent absences, the impact of even short-term absences on autistic children can be hugely detrimental to their learning, wellbeing and smooth transition back to school. One parent told us that her child was excluded from school for two days, but he never returned to school after this because he lost all faith in the school. Missing only a few days of school work can still be significant, particularly for those in the later years of their school education due to the increased focus on academic attainment.

It is undeniable that the length of absences experienced by some children are unacceptably long. More than half of those who had been placed on part-time timetables were on them for more than six months. This prolonged use of a reduced timetable raises questions as to the purpose and effectiveness of this approach in meeting these children's educational and support needs. Some children have missed more than a year of school education altogether.

Frequency of absences

The number of absences that some individual children had experienced was also concerning. Nearly three quarters of children who had been formally excluded from school had been excluded on more than one occasion. Multiple exclusions indicate that issues have not been resolved and effective strategies to prevent further exclusions have not been successfully put in place. For children who are being unlawfully excluded, a striking 85% said that this had happened more than once, with almost a quarter saying that this had happened more than once in the same week. Comments left by parents suggest that this is happening on a daily basis for some children.

Understanding of autism and its impact on behaviour and communication

Nearly three quarters of parents who responded to the question on what would have made the biggest difference to their child said school staff having a better understanding of how their child's autism affects them, including their communication needs. A similar number felt that a better general understanding of autism was also important.

With this in mind, it is of interest to consider a recent landmark case relating to exclusion heard in the Upper Tribunal in England. The National Autistic Society intervened in this case, brought by the family of an autistic child, to challenge a loophole in the Equality Act that meant schools didn't have to make reasonable adjustments for disabled children when they have a 'tendency to physical abuse' - even when that behaviour is down to a lack of appropriate support.

The National Autistic Society argued that 'challenging behaviour' should be more accurately be seen as 'distressed behaviour'. The judge stated in her ruling: *"To my mind it is repugnant to define as 'criminal or anti-social' the effect of the behaviour of children whose condition (through no fault of their own) manifests itself in particular ways so as to justify treating them differently from children whose condition has other manifestations."*

Lack of appropriate support

A common theme in comments from parents related to the perceived lack of appropriate support available to their child in school. Many respondents told us that they had made the decision to keep their child at home, either because they did not feel there was adequate support in place or that their child's school was the right placement for them. This is a parental decision, and we are unable to tell from this survey what steps parents, schools or others may have taken to address any concerns before things reached this stage. It is, however, concerning to note the number of families who felt their child was unsupported to the extent that they should not attend school.

Similarly, some parents told us that it had been their decision for their child to go on to a part-time timetable. Comments suggested that while some parents had felt this was a positive strategy for their child, others felt they had no choice or were generally unhappy with the arrangement.

Out of school education provision

A common theme across all types of absence was that no or very little support was given to catch up on any school work while children were absent. While this would not have been appropriate for all children and may not have been necessary for some children whose absence was for a very short period, there are many situations where children out of school can still access education in a way that meets their needs and ensures they do not fall behind their peers. We can see from the comments describing the impact on children that falling behind and missing out on learning were key concerns. Across all types of absence explored here, an average of 86% of children did not receive support to catch up on work they had missed.

Involving parents

When asked about support to return to school for those that had been off, we found that many parents had not been involved in discussions about their child's support. In the case of part-time timetables, 80% of parents had not been told how long their child would be on a part-time timetable for. Parents should be seen as vital partners in their child's learning, and when the impact of a child being off school can be so great on children and on their families, these situations should be some of the most crucial times to involve families in discussions.

Impact on wellbeing

In considering the impact of autistic children missing school, it is worth looking at the parental responses against the Scottish Government's own Getting it Right for Every Child (GIRFEC) wellbeing indicators:



We found instances of absences from school being detrimental across all eight wellbeing indicators.

The volume and content of the parental comments we received about the impact missing school has had on their children - and the fact that some families are left feeling they have little choice but to keep their child at home - clearly demonstrate that the wellbeing needs of a significant number of autistic children are not being met. The wellbeing of some autistic children may be being actively harmed by their experiences of school. The high number of children missing school due to anxiety, or who are refusing to attend school, suggests that there are issues at school that are not being addressed for these children. It is clear from the results of the survey is that parents are very concerned about the detrimental effect missing school has on their child's learning, development and future life chances. There is also real concern about the wider impact on children's mental and physical health and wellbeing with concerns about their children feeling isolated and finding it difficult to make and sustain friendships highlighted.

Next steps

For a significant number of autistic children, school does not seem to be a place they feel welcomed, included or safe, and some are happier when they are off school. The consistency of issues reported highlights that these situations are not rare occurrences felt by a small number of pupils, but something that many children and their families are familiar with and struggling to deal with.

“My daughter is behind in all her subjects and looks likely to not achieve any qualifications this year. This has increased her anxiety levels and is having a knock-on effect on her ability to attend school.”

“She became more depressed and anxious and no-one asked about her or cared about her.”

The number of autistic children missing out on their education is unacceptable, and the different type of absences described in this report are only some of the ways that autistic children are being denied access to their education. Parents’ responses point to real concerns that even when their children are physically in school they are not included, engaged or involved in learning or in school life.

“Harder to get back into school but his anxiety can be so overwhelming, and he can self-harm that he has been safer and calmer at home.”

“He feels alienated and treated differently from other pupils. He says he is a “bad boy”. Finds it difficult to catch up (he also has dyslexia and ADHD) so falls further behind with his work. Then he feels he doesn’t want to go to school as everyone calls him stupid.”

Our evidence offers an insight into actions that are needed to change this situation to ensure autistic children’s rights are upheld and they are given the support they need. Scottish Autism, the National Autistic Society and Children in Scotland feel the following action is required as a matter of urgency.

“He preferred home and was no longer anxious when off school. Although he was off school, he is often sat out or not allowed to join in classes anyway so all he missed was punishment.”

“Falling behind with work, difficulty integrating with peers, missing transition activities. Gaps in his learning. Impacted his self-esteem. Doesn't feel valued or included.”

CHAPTER 7 - WHAT SHOULD HAPPEN NEXT

The evidence in this report shows that autistic children are facing significant barriers to accessing their rights to education and support, and that these are not isolated problems. It is clear that there is widespread practice that is not in line with Scottish education policy and law and the resulting impact is detrimental on autistic children.

The findings in this report should also not be viewed in isolation. The data contributes to the growing body of evidence that there are systemic issues in the provision of education in Scotland impacting on outcomes for children with additional support needs on a daily basis. We do not believe that the issues lie with one professional group and recognise the pressures for those working to deliver “excellence and equity for all”.

Calls for action

We believe that autistic children should be included, engaged and involved in their education. The nine calls for action set out below will help to make this a reality. These calls, if listened to, will have a positive impact on the education of **all** children with additional support needs, particularly those that are missing out on their education.

Call 1: Stop the use of unlawful exclusions and inappropriate use of part-time timetables

In order to reduce the use of unlawful exclusions and inappropriate use of part-time timetables, there must be a robust system for monitoring these practices and holding schools and local authorities accountable should their use continue. We therefore call for the following action:

- The Scottish Government should make sure that the different types of absences are recording accurately, avoiding the use of a catch-all category of “authorised absences”. This can be done by amending SEEMIS, (the Education Management Information System (MIS) system in Scotland). The resulting information should be included in the annual exclusions data published by the Scottish Government.
- Local authorities’ staged intervention processes should be enhanced to build in trigger points where further action must be taken should a child be out of school. For example, children sent home more than twice a term would trigger a review of support.

-
- The school inspection process should require schools to evidence that they are regularly monitoring all children out of school, the hours of education missed and the support that is being provided to learn, and to return to school. Schools should be evaluated on the strength of their practice in preventing and managing avoidable absence from school.
 - As part of the review of Included, Engaged, Involved Part 1: Attendance at Scottish schools, clear parameters for the use of part-time timetables should be developed, including agreed procedures should a child be on a reduced timetable for longer than an agreed period.

Call 2: Reduce the number of formal exclusions of children with additional support needs

Exclusions should happen only as a last resort, when schools have tried every other practical solution. The number of children with additional support needs excluded from school is consistently higher than for children who do not have additional needs. To address the use of formal exclusion with children with additional support needs, the following action is needed:

- The Scottish Government should revisit Regulation 4 of the Schools General (Scotland) Regulations 1975¹ which gives the power to exclude and sets out the circumstances under which a pupil may be excluded. Regulation 4 currently does not mention children with additional support needs and is not in line with the exclusions guidance Included, Engaged and Involved Part 2. Nor does it take into consideration the issues noted in the recent Upper Tribunal decision in England that distressed behaviour may not be a choice for autistic children and is often an indication that a child's needs are not being met.
- The Department for Further Education has funded resources designed to support schools in England to avoid formal exclusions of autistic children. The Scottish Government should fund the replication of these resources for use in Scottish Schools.

Call 3: Improve the availability of specialist teachers

As discussed earlier the number of teachers specialising in learning support and additional support needs has reduced considerably since 2010. We believe the reduction in these posts is significantly impacting on children with additional support needs. In order to address this immediate action is required:

- The Scottish Government should commission a short-term working group to develop a plan for the additional support for learning workforce published within 1-year of this report. The plan should include a commitment to increase trained additional support for learning teachers to 2010 levels (as a minimum) within 2 years.
-

Call 4: Review of the availability of appropriate placements for autistic children

The vast majority of autistic children will be educated in mainstream schools, but mainstream environments may not be suitable for all autistic children.

To ensure the availability of suitable placements for autistic children:

- The Scottish Government should make adequate investment in education to enable local authorities to make school placement decisions based on individual needs, rather than on what resources are available. We support recent increases in monies made available but further investment is needed.
- Local authorities must review their approach to planning specialist provision for autistic children. Data from the improved recording of children out of school (as outlined in our first call) should be used to inform whether a child's current school placement is suitable to meet their needs. Specific consideration should be given to provision for autistic pupils who are academically able but find that mainstream school is not a suitable learning environment.

Call 5: Enhance programmes of initial teacher training and Continual Professional Development to improve understanding of autism

In their 2017 report *How is additional support for learning working in practice?*³¹, the Scottish Parliament Education and Skills Committee concluded that some of the proposed changes to initial teacher training could further limit the time available to trainee teachers to train in additional support for learning. Currently, there is no requirement for new teachers in Scotland to learn about autism.

We believe that in order to meet children's needs, education professionals must have a better understanding of autism.

- The General Teaching Council for Scotland should ensure all trainee teachers receive training on additional support for learning which includes a compulsory element on supporting autistic children.
- The Scottish Government should implement a model of continuous professional development in autism understanding for education staff, similar to the Autism Education Trust which is funded in England by the Department for Education and has trained over 150,000 staff.³²

³¹ How is additional support for learning working in practice? Recommendation 20 (Scottish Parliament, 2017): http://www.parliament.scot/S5_Education/Reports/ASN_6th_Report_2017.pdf

³² <https://twitter.com/educationgovuk/status/979298982718558209>.

Call 6: Reinstate a minimum number of hours of education for children out of school

Currently there is no legal requirement to provide a minimum number of hours of education support to children out of school. In previous guidance³³, it was suggested that children too ill to attend school should expect 3-7 hours per week while absent.

- The Scottish Government should set a minimum number of hours of education support for children out of school. An agreed framework for when this support should start should be developed.
- The Scottish Government should allocate funding for local authorities to recruit staff to provide educational support to children missing school.

Call 7: Improve access to online learning

While it will not be appropriate for every situation, we believe that online learning opportunities are not at present being utilised to greatest effect to ensure that those who are missing school, for whatever reason, are still given the opportunity to learn.

- Education Scotland should commit to improve current digital educational resources to support the remote teaching of Curriculum for Excellence, including identifying any specific gaps in the current offer.

Call 8: Use of whole school approaches to raise awareness and understanding of pupils with additional support needs, including autism

If mainstream schools are to be truly inclusive settings, then everyone in the school community needs awareness of autism, disabilities and additional support needs, including all pupils.

- Schools must build in awareness of additional support needs in general and autism in particular into the health and wellbeing aspect of the curriculum to support inclusive school environments, where everyone feels their individual needs are understood and respected.

Resources available:

The Autism Toolbox: www.autismtoolbox.co.uk

The National Autistic Society's MyWorld teaching resources: www.autism.org.uk/myworld

³³ Scottish Government Circular 5/2001 - Guidance on education of children absent from school through ill health (no longer publicly available)

Call 9: Awareness raising of children's rights to additional support for learning with children, young people and families

It is vital that children, young people and their families are aware of a child's right to a school education and additional support with their learning should they need it. This report highlights many instances where this has not happened.

- The Scottish Government must make sure that local authorities adhere to Section 26 of the ASL Act³⁴ and the accompanying Additional Support for Learning Ministerial Information Order³⁵ which place duties on local authorities to publish information about their additional support for learning policies and provide details of Enquire, the Scottish advice service for additional support for learning, the Scottish Independent Advocacy Alliance and the Govan Law Centre.

Support available:

Enquire helpline **0345 123 2303** and websites **www.enquire.org.uk** **www.reach.scot**

National Autistic Society's Education Rights Service, **0808 800 4104**

www.autism.org.uk/educationrights

Scottish Autism Advice line **www.scottishautism.org** **01259 222022**

Further actions needed

Supporting good practice

We acknowledge that many autistic children are accessing their education and that parents, carers, schools and local authorities are working successfully together to ensure children have the support they need to get the most from school. We feel more could be done to share this good practice. We ask that Regional Improvement Collaboratives take a lead in identifying good practice across their areas and, supported by Education Scotland, implement systematic approaches for improvements across all sectors.

Improved access to mental health services for autistic children

Many parents told us that they felt the reason why their child had been out of school was due to anxiety. Parents in this survey also described the negative impact that the time out of school can have on their children, including increased stress, anxiety and depression³⁶. SIGN Autism Guidelines (2016)³⁷ state that autistic children may have additional developmental disorders, medical problems or emotional difficulties and should have access to the same range of therapeutic interventions as any other child.

³⁴ Education (Additional Support for Learning) (Scotland) Act 2004 section 6: <https://www.legislation.gov.uk/asp/2004/4/section/26>

³⁵ The Additional Support for Learning (Sources of Information) (Scotland) Order 2016: <http://www.legislation.gov.uk/ssi/2016/299/contents/made>

³⁶ It should be recognised however that for some children, being out of school was felt to reduce stress levels.

³⁷ SIGN 145: Assessment, diagnosis and interventions for autism spectrum disorders (2016) <https://www.sign.ac.uk/assets/sign145.pdf>

We were pleased to see the recommendation in the recently published Audit of Rejected Referrals to CAMHS³⁸ that relevant and responsible bodies should review their mental health services to ensure they are available for autistic children and young people. We believe that the Scottish Government's CAMHS Taskforce must consider how CAMHS can be made more accessible for autistic children to remove the unacceptable barriers to care and support that currently exist.

Research should also be undertaken into other interventions, such as assistive technologies, that could be used to support young people in managing anxiety and ensuring they can attend school. One example of this technology is Brain in Hand which is used in England to support children with anxiety issues in school.

Improved access to support for families of autistic children out of school

The emotional, practical and economic impacts on families that result when a child is out of school are evident from the testimonies of parents who responded to the survey. We believe that if our calls to action are followed, there should be many fewer instances of autistic children missing school. However, we are aware that there may be instances where a child will be out of school for a period of time due to mental or physical health issues. We therefore believe that local authorities should establish procedures to make sure that the families of autistic children who are out of school for prolonged periods are given information about local and national support services.

Particular attention to be paid to learning from projects such as Scottish Autism's *This is me* project which was funded by the Autism Strategy Development Fund. The aim of the project was to understand the reasons young people were out of school and to support families, schools and pupils to return.

Research with autistic children and young people

This report provides powerful evidence about the impact of autistic children missing school from parents' perspectives. To create a full picture of the impact of exclusions on autistic children and what would help them feel supported and attend school requires hearing from them and talking to them directly.

The Scottish Government should work with children's organisations with the skills to engage with autistic children and fund research to gather and report on autistic children's views. The Scottish Government should further commit to taking on board what children and young people say and use their views to shape future policy and practice.

³⁸ Rejected Referrals to Child and Adolescent Mental Health Services (CAMHS): A Qualitative and Quantitative Audit (Scottish Government, 2018)
<https://www.gov.scot/Publications/2018/06/3260>

Review current research on the perspectives of the education workforce

This report only provides one side of the picture in understanding the reasons why many autistic children are missing out on their education. To build a fuller understanding, it is important to hear from teaching staff and other staff who support autistic children about what the barriers are for them in meeting the needs of autistic pupils. We do not think new research is required. However, as part of the development of the additional support for learning workforce plan suggested in Call 3, a systematic review of the existing evidence should be carried out to identify priorities for education staff.

Research to explore unlawful exclusions for children and young people with other additional support needs

Evidence from calls to the Enquire helpline and other advice services indicate that it is not only autistic children who experience unlawful exclusions and miss school, and that it affects children with a range of other additional support needs including ADHD and mental health problems. Improvements to SEEMIS recording systems will help to better understand the nature and extent of unlawful exclusions across all additional support needs. However, to fully understand the impact these exclusions are having on children with specific support needs and their families will require additional research.

Investigation into the impact of early diagnosis on experience of school

A concerning number of children who received a relatively early diagnosis are reflected in the survey data. For these children, early identification does not appear to be a protective factor in experiencing challenges at school. We believe that there should be further investigation into this finding, with a particular focus on practice relating to transition into primary school.

This document and the Executive Summary is available online at www.notengaged.com



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autism